In/validating disability: changing labour markets and out of work disability benefits

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Abstract

This thesis is concerned with the relationship between the political economy and UK governments' approaches since the 1970s to out-of-work disability benefits. It uses a historical materialist analysis of both the current mode of production and the social model of disability to understand how and why there is a disconnect between government approaches to disability and disabled people's lived experiences. The concept of a 'validating device' – the mechanism used to determine who is exempt, on the grounds of disability, from having to seek employment - is utilised to analyse changes in out-of-work disability benefits and the accompanying assessments.

The thesis pulls together four different areas of study which are key to understanding why the disconnect has occurred. The first area of research and analysis relates to the position and importance of the administrative category of disability to the functioning of capitalism, arguing that it is impossible to fully understand the current position of disabled people who are unable to engage in waged labour without considering their role and position in the capitalist mode of production. The second area is strongly linked to the first and concerns the history and current situation of out-of-work disability benefits in the UK, making links with what is known about changes in the labour market. The third area uses documentary analysis to chart the development of the conceptual framework underpinning the current validating device, the Work Capability Assessment, showing how a system was created which treats disabled people's experiences as contentious. The fourth area directly relates to disabled people's experiences of the assessment process. Data from focus groups, interviews and online surveys explores both how people experience the assessment and the nature of the relationship that is created by the validating device.

The thesis concludes that changes in the determination of who is eligible for out-of-work benefits have been driven primarily by developments in the political economy rather than by individual capacity or need; and that it is there is a consequent disconnect between current policy approaches to disability and disabled people's lived experiences. It argues that neither previous developments nor the current situation can be understood without a wider

analysis which places disabled people's experiences in the context of past and current developments of the capitalist mode of production.

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Key to Abbreviations

BCODP	British Council Of Disabled People
BPS	Bio-Psycho-Social
CAB	Citizen's Advice Bureau
DIG	Disability Income Group
DPAC	Disabled People Against the Cuts
DPO	Disabled People's Organisation
DWA	Disability Working Allowance
DWP	Department of Work and Pensions
GP	General Practitioner
ESA	Employment and Support Allowance
ESRC	Economic and Social Research Council
GDP	Gross Domestic Product
HCP	Health Care Professional
IB	Incapacity Benefit
IVB	Invalidity Benefit
JSA	Job Seeker's Allowance
MR	Mandatory Reconsideration
NCIP	Non-Contribution Invalidity Pension
NHS	National Health Service
OECD	The Organisation for Economic Cooperation and Development
ONS	Office of National Statistics
OT	Occupational Therapist
PCA	Personal Capability Assessment
SDA	Severe Disablement Allowance
UK	United Kingdom
UPIAS	Union of the Physically Impaired Against Segregation
WCA	Work Capability Assessment
WRAG	Work Related Activity Group

Introduction

This research was partly inspired by my own experiences of the assessment process for firstly Incapacity Benefit and then Employment and Support Allowance. I found these assessments humiliating, and they left me feeling ashamed and fearful. I was confused by both their lack of understanding of my impairment and how the questions asked seemed to bear no relationship to my capacity to work. I wanted to understand why it was that I was being placed in a situation where someone else had the right to redefine my lived experience of both my impairment and disabling barriers.

This research deals with two key issues and how they relate to each other. The first is the relationship between shifts in the economy and the labour market and changes in out-of-work disability benefits. The second is disabled people's experiences of, and the assumptions underpinning, the current assessment process for out-of-work disability benefits. It will examine how changes in the labour market relate to changes in the numbers claiming, and government approaches to, disability benefits and use documentary analysis to explore how and why the Work Capability Assessment takes the form that it does. It will then examine disabled people's experiences of this assessment in order to understand the relationship that is being played out in the process by which the state determines who is officially recognised as eligible for out-of-work disability benefits.

My thesis is that changes in the determination of who is eligible for out-of-work benefits in the United Kingdom have been driven primarily by developments in the political economy rather than by individual capacity or need; and that there is a consequent disconnect between current policy approaches to disability and disabled people's lived experiences.

The disconnect here refers to the extent to which the policy approach, enactment (via the Work Capability Assessment), and outcome all fail to understand or incorporate disabled people's experiences of their impairments; the various ways they impact on obtaining and sustaining waged employment and why and how such barriers exist. The thesis is that the outcome of this disconnect is not just a system which fails to understand these issues, but one which arguably produces and reproduces disability – as understood as the social oppression experienced by those with impairments.

An important aspect of this research is the combining of different areas of analysis in order to develop a deeper understanding of how and why this disconnect has arisen. As such my research questions aim to use each section of the thesis to gather an understanding of how they all interact and why.

My guiding research questions are therefore:

1. What is the relationship between changes in the administrative category of disability and the political economy in the UK and why is this relationship important? This is the focus of Chapters 2 and 3.

2. Why and how does the Work Capability Assessment take the form that it does? This is the focus of my documentary analysis in Chapter 5.

3. How does the theoretical and conceptual framework of the Work Capability Assessment impact on disabled people's lived experiences? This is the focus of my analysis of data derived from focus groups, interviews and an online survey in Chapters 6 and 7.

4. Why does the disconnect between the WCA and disabled people's lived experiences exist and how might it be addressed? This is addressed in Chapter 7 and 8.

1971 has been chosen as a useful and practical starting point for the analysis of changes in the labour market and in out-of-work disability benefits. This marks the first introduction of an out-of-work disability related benefit not restricted to the concept of a compensation pension for those who had

acquired an impairment through work or war. The 1970s also saw the beginning of a dramatic shift in the economy and in the structure of the British labour market.

Policy Context

Public support for those who are not engaged in waged labour has always been contentious but, as the post-war consensus on the welfare state was eroded and claimant numbers increased, support for those exempt from work on the grounds of disability also became a politically contentious issue. This shift was apparent in the early 1990s when the then Prime Minister questioned whether all those who were on Invalidity Benefit (one of the fore-runners of the current Employment and Support Allowance) were really 'invalids' (Major, 1993, col 732). This type of questioning has characterised much of the policy debate since then, but the controversial nature of the issue intensified after the 2010 general election when the full roll-out of Employment and Support Allowance (ESA) and the Work Capability Assessment (WCA) was accompanied by significant protests by disabled people and their organisations.

Governments have been attempting to reduce the numbers of people on out-of-work disability benefits since 1994 (prior to that the focus was mainly on reducing the number on unemployment benefits). They have done this by changing the assessment which determines eligibility: the Conservative government introduced an All Work Test in 1994, followed by the Labour government's Personal Capability Assessment in 1998, which was then replaced by the Work Capability Assessment in 2008, accompanied by an intensification of the rhetoric about who 'deserves' to receive such benefits. When the Labour government first introduced the WCA their aim was to reduce the numbers claiming by one million (Department for Work and Pensions, 2006), an aim repeated ten years later by Iain Duncan Smith, then Conservative Secretary of State for Work and Pensions, when he claimed that the WCA was flawed after it became clear that - like the previous assessments - it had not achieved the reduction that governments intended (Duncan Smith, 2015, no pagination).

At the time of writing, in late 2017, the government is introducing yet another change to the system of accessing out-of-work disability benefits. It has suggested that the WCA needs reform and in the meantime has introduced a new stage to the process of claiming, the Health and Work Conversation, which applicants will be required to undergo while waiting for their Work Capability Assessment. The rationale for this reform, like its predecessors, raises questions about its relationship to either the reality of today's labour market or to the lived experiences of disabled people and to addressing barriers to employment.

Structure and content

After setting out the theoretical approach in Chapter 1, the first section of this thesis comprises a critical analysis of, firstly, changes in the labour market and how these impacted on disabled people (Chapter 2), and secondly changes in approaches to out-of-work disability benefits (Chapter 3). It then moves on in Chapter 4 to describe the methodological approach to analysing the theoretical and conceptual development of the Work Capability Assessment, and to my research on disabled people's experiences of applying for Employment and Support Allowance. This is followed by documentary analysis to interrogate why the WCA takes the form that it does (Chapter 5), and then by Chapters 6 and 7 which concern the experiences of the WCA recounted by the 343 people who took part in either a focus group, interview or online survey. My concluding Chapter 8 summarises the research and analysis and also identifies some changes that would be required if the current disconnect between official approaches to disability and disabled people's lived experiences is not to be repeated by the next stage of reform to out-of-work disability benefits. However, the chapter ultimately argues that the current mode of production is what drives this disconnect and therefore a fundamental change to the mode of production is required.

 A brief summary of the chapters is given below.

Chapter One sets out my theoretical approach. The thesis is grounded in a historical material analysis and understanding of both the concept of disability and the capitalist mode of production, and how these two interact. This chapter

explains how I will use this approach, and specifically the concept of the reserve army of labour, to explore disabled people's current situation in relation to the labour market. I discuss the relevance of a social model of disability to a historical materialist approach and also address the issue of whether the social model can encompass the experiences of people with long-term health conditions. Finally, the chapter introduces the concept of a 'validating device', a term used by Deborah Stone (1984) to describe the mechanism which determines the administrative categorisation of disability (that is, those who are exempt, on the grounds of disability, from having to seek employment) and its importance to the development of capitalism.

Chapter Two This chapter is concerned with a critical analysis of how the labour market in Britain has changed since the 1970s and how this has impacted on the employment rates and opportunities of disabled people. It examines the extent to which disabled people have been pulled into the active reserve army of labour and whether changes in the labour market have made it harder for disabled people to move into and retain waged work. The chapter analyses the changes in governments' concerns with levels of employment and unemployment amongst disabled people in the context of both the varying demands for labour and the economic and political consequences of public expenditure. The chapter discusses some of the developments in employment support which aim to increase disabled people's employment opportunities, but the central focus of this thesis is the policy approach and enactment of assessments for out-of-work disability benefits (which is the subject of the next chapter).

Chapter Three This chapter builds on the analysis in chapter 2 of changes in the labour market and the consequences for numbers claiming out-of-work disability benefits. It uses Stone's concept of 'validating devices' (used to determine the administrative category of disability) and the work based and needs based distribution systems, to analyse how UK governments have approached the tensions between the two systems and the different 'validating devices' used to determine who is exempt from selling their labour. The chapter will discuss the various reforms different governments have introduced which are aimed at reducing the numbers claiming out-of-work disability

benefits. The chapter identifies common themes and differences in their approach towards both disabled people and to out-of-work disability benefits, and will also examine what changes have taken place in public attitudes towards welfare spending in general and disability benefits in particular. It will argue that the labour market changes and dominant political responses to public expenditure pressures identified in chapter 2 required a reconstruction of the administrative category of disability, a redefining of 'the really disabled'.

Chapter Four This chapter sets out the methodological approach and methods used for the primary research. Firstly, it describes my approach to the analysis of six documents which are identified as key to the development of the Work Capability Assessment, the 'validating device' first introduced in 2008 and which has been crucial to redefining who is exempt from selling their labour. It then discusses the use of focus groups, individual interviews, and an online survey – which used twitter as a method for recruiting participations. It identifies both the strengths and weaknesses of each of these methods which were used to gather data on individuals' experiences of the WCA. Finally, the chapter reflects on the limitations and lessons learnt from researching individuals' experiences and discusses the rationale for how the data generated was analysed and presented.

Chapter Five This chapter examines the development of the theoretical underpinnings of the Work Capability Assessment (WCA) – the current 'validating device' - and uses this to explore how and why the WCA takes the form that it does. It examines this development through a documentary analysis of six key texts, tracing the evolution of the theoretical and conceptual framework which resulted in the WCA. This examination helps give a further insight and understanding to why the disconnect exists. It shows an ideological approach which views disabled people's experiences as 'contentious' and 'irrelevant' to the assessment process. This analysis helps to explain the findings from the data generated by focus groups and the online survey about individuals' experiences of the WCA.

Chapter Six This chapter shows how the theoretical and conceptual framework analysed in Chapter 5 plays out in practice via the experiences of those going

through the assessment process. It uses a literal analysis of the data gathered via the focus groups, the interviews and the online survey to present the reality of disabled people's experiences of the WCA. The focus groups and interviews generated detailed information about the experiences of the WCA but so too did the online survey because many of the 330 respondents used the opportunity to write at length about their experiences. It documents a distressing and invalidating experience, which not only is inadequate at assessing someone's capacity to work, but that causes additional harm to those going through it.

Chapter Seven This chapter uses the data from people's experiences to give a wider understanding of how the theoretical and conceptual framework of the WCA impacts on disabled people's lived experiences. In doing this it illustrates the nature of the relationship between the State and people claiming out-of-work disability benefits. It shows a system which denies disabled people agency, prioritises government policy aims over both disabled people's and clinician's expertise, and creates a form of institutional stigmatisation.

Chapter Eight This concluding chapter summarises the findings from the research and analysis. It then goes on to examine very recent changes in the process of claiming out-of-work disability benefits identifying the current direction of travel for the validating device and implications for those claiming. The chapter finishes by looking at whether better ways can be identified of constructing a validating device. However, it argues that these would merely be tinkering around the edges as any changes to such a device will experience similar problems unless there are fundamental changes to both the way work is defined and, more importantly, to how individuals' worth, their value, and even their basic humanity is recognised.

What makes this thesis distinctive?

There has been much criticism of the Work Capability Assessment since its full introduction in 2010, and to a large extent the experiences of the participants in this research confirm these existing criticisms. However, this thesis is distinctive in a number of ways, particularly because it establishes that the state's approach

to disability is determined by the current stage of the capitalist mode of production.

The thesis uses, draws together and aims to build on previous research and analysis in four different areas of study which, it argues, are all essential to understanding the role of the administrative category of disability in the form of eligibility for out-of-work disability benefits. It is this drawing together of different areas into one overarching analysis which makes this thesis distinctive, a contribution that is key to understanding why there is such a disconnect between government policy and disabled people's lived experiences of these policies.

The first area of research and analysis relates to the position and importance of this administrative category of disability to the functioning of capitalism. This thesis argues that it is impossible to fully understand the current position of disabled people who are unable to engage in waged labour without considering their role and position in the capitalist mode of production. Those unable to work due to impairments and/or health conditions have always played a certain role in the capitalist system and the thesis places the WCA in the context of the role that it plays in the current stage of capitalism. It builds on both Marx's concept of the reserve army of labour and Stone's analysis of the administrative category of disability, which serves as a mechanism determining who is in the needs-based or work-based distribution system. It shows the importance of a validating device, such as the WCA, to the functioning of capitalism and also draws on work by Russell (2001) and Grover and Piggot (2005) in examining the role of welfare reform and the reserve army.

The second area is strongly linked to the first and concerns the history and current situation of out-of-work-disability benefits in the UK, making links with what is known about changes in the labour market. Here it uses and builds on the work of people such as Beatty and Fothergill (1994; 2014) who have written extensively on why there was an increase in claimant numbers and what their relationship is to the labour market. It also uses work by Baumberg (2014) who makes links between the shifts in the type of work that is available and the main impairment of those claiming out-of-work disability benefits. In doing so, the thesis examines the links between changes in the labour market, their impact on disabled people and out-of-work disability benefits.

The third area relates directly to the ideological underpinnings of the assessment process. While other researchers and commentators have argued that the WCA is based on a biopsychosocial model, analysis of key documents in Chapter 5 shows the development of the theoretical framework which resulted in the WCA, and illustrates how and why it diverges from the BPS. The analysis charts the development of a politically constructed narrative of claimants with 'common health problems' in which their experiences of illness and/or impairment are considered to be 'contentious' and the largest barrier to work to be their 'choice and intent'.

The fourth area relates directly to disabled people's experiences of the WCA. Here it adds to some very important previous work (such as Spartacus network 2012, 2013; Hale 2014; Inclusion London 2014; Marks et al 2017) which has shone a light on this assessment process. Survey data presented in Chapter 6 brings together all these different areas to illustrate how the politically constructed narrative described in Chapter 5 is played out in the assessment process and how this is experienced by those going through it. In addition, the interpretative reading of the survey data, presented in Chapter 7, interrogates the nature of the relationship which results between the state and disabled citizens who cannot sell their labour.

The thesis therefore goes beyond illustrating how ESA claimants experience the WCA, important though this is to highlight (as in Chapter 6). Instead, it is centrally concerned with why the WCA takes the form that it does. In order to address this, the thesis analyses changes in the labour market, their impact on disabled people and examines the links with the administrative category of disability. It draws and builds on existing research on the history and current situation of out-of-work disability benefits in the UK, making links with what is known about changes in the labour market. However, it also argues that neither previous developments nor the current situation can be understood without a wider analysis which places disabled people's experiences in the context of past and current developments of the capitalist mode of production. A further distinctive factor of this thesis is that I have personal experience of both the current and previous assessment process for out-work-disability benefits.

A note on terminology

There are a number of words and phrases used in this thesis which have a contested definition and usage. This Note aims to briefly explain how they are being used and understood within the context of the thesis and the reasons behind doing so. All of these terms could probably have entire research projects written about their histories, definitions and use. The less ambitious intention here is to provide clear, albeit brief, explanations for why I am using these terms.

One of the problems found when trying to define the terms used is a tension between trying to understand something from a social model perspective (a perspective which is explained in Chapter 1) and how people with a certain impairment may wish to define their experience and describe themselves. These tensions are often created and/or exacerbated by the fact that, in order to get access to any required support, people have to operate within a framework which uses a medical model approach and the associated language is used as a form of recognition and validation of their needs.

What follows is a list of words and phrases I have used with a brief explanation as to why I have used them.

Disabled people

I use the term 'disabled people' as this is a reflection of the social model of disability, a key perspective which underpins my approach to the thesis and which is further explored in Chapter 1. Within the social model of disability, 'Disabled people are those people with impairments who are disabled by society' (Thomas et al, 1997, no pagination). Although those who first articulated the social model conceived it in relation to people with physical impairments, stating 'it is society which disables physically impaired people' (UPIAS, 1976, no pagination), the model has since been extended so that impairment is taken to mean 'people with learning difficulties, physical impairments, sensory impairments, facial disfigurement, speech impairment, mental illness, mental distress (Thomas et al, 1997, no pagination). The term

'disabled people' is intended to convey the sense that it is barriers, external to the individual, which create social and/or economic disadvantage rather than impairment in itself.

Mental health condition

This has been one of the hardest terms to decide on and define. There is yet to be a widely agreed upon term within disability studies and by people with mental health conditions themselves. There continues to be much discussion around how to fit mental health into a social model of disability (see for example Beresford et al 2016; Graby 2015). The term mental health condition has been chosen for a number of reasons. Firstly, it is a simple straightforward term. I did consider using 'people with experience of mental and emotional distress' as this is a largely inclusive term and does not necessarily label something as a problem located within the individual, as the distress can be caused by the social context in which they live. However, it is rather clumsy and is not a term which is widely adopted by those whose experience it purports to describe.

Secondly, as mentioned in the introduction to these definitions, some use of language is related to recognition and validation and many people who do experience mental and emotional distress emphasise the need for recognition - in the sense of a medical diagnosis - of their mental health condition. This is a particularly important point in the context of the ideas underpinning the Work Capability Assessment, which will become clear in Chapter 5.

I do however recognise that there are some problems with using the term mental health condition. It could be said to be medicalised language and to locate the 'problem' as being within the individual. However, I am defining language used for different impairments and, although the cause of the mental health condition may be socio-economic, the term is being used throughout the research, both from a policy and research participation position, to describe an impairment group (using the word 'impairment' in social model terms as defined above).

Terms such as service users/survivors were also considered but ultimately rejected as not everyone who has a mental health condition will have had access to these services, and some of those who have had access may not

consider themselves to be survivors. For instance, some people feel services helped them (and therefore feel the term is too negative about services), while others do not feel that they 'survived' what was a negative experience of services.

Another consideration from a social model understanding could have been psychological impairment, however the use of the word impairment outside of the social model of disability is much more understood as something permanent and some of the contentious debates concerning mental health are about recovery and the potential permanence or not of a condition. Condition is also arguably more neutral than the term illness. However, I remain somewhat dissatisfied with the use of the term mental health condition, but for the purpose of this thesis it is the one which is used.

People with learning disabilities/difficulties

This was another very contentious term to decide upon. Social model language would probably suggest referring to 'people with cognitive impairments', although Goodley (2013) argues cognitive impairments are socially and culturally produced. Goodley also argues for the term learning difficulties as being one people with such impairments themselves use. However, the organisation I worked with to try and arrange one of my focus groups is one of the few organisations run by people with learning disabilities and this is the term that they use to describe themselves. This is partly because the term 'learning disability' brings with it recognition of needs in the context of accessing support and the term is therefore linked to the issue of recognition and validation, as mentioned above in the context of mental health.

Both learning difficulty and learning disability are used in the context of discussions and campaigning on government policies and, in contrast to the term 'cognitive impairment', are arguably the most socially understood. So, whilst neither term fits strictly within a social model approach, but because each term is widely used by people with cognitive impairments themselves, I have chosen to use both terms for pragmatic reasons of wider understanding.

Chronic or long-term health conditions

While I do not exclude people with chronic or long-term health conditions from a social model perspective, it is important to use language which reflects the insistence by some people with such experiences that 'people differ in the degree to which disability [i.e. disabling barriers], rather than impairment, is the main source of their exclusion from society' (Hale, 2015, no pagination). A key part of the campaigning against welfare reform from 2010 onwards was carried out by people who insisted on a recognition of their impairments stemming from long-term ill health. The context was, as Catherine Hale put it, a need to recognise that some people 'can't work chiefly because of their defectively-functioning bodies, and that employer attitudes and adaptations to work or workplace don't make a significant enough difference to their employability' (Ibid). As will become clear from both the analysis of the development of the Work Capability Assessment, and the experiences of those undergoing the assessment, many people feel that their experience of their body is being denied. By using the terms 'chronic illness' and 'long-term health conditions' I am therefore signaling a recognition of people's own definition of their reality.

Chapter 1: Theoretical Approach

Introduction

The approach to this thesis is grounded in a historical material analysis and understanding of both the concept of disability and the capitalist mode of production and how these two interact. It will use this to understand disabled people's situation in relation to the labour market and why the government's policy approaches do not match disabled people's lived experiences. This chapter aims to explain what understanding of these concepts is being used and also introduces a number of other concepts which are key to the thesis. These are the social model of disability, the reserve army of labour, validating devices and the administrative category of disability.

1.1 A historical materialist approach to disability

Historical materialism grew out of Hegel's understanding of history and society which, he argued, was explained through dialectical idealism. Dialectical idealism saw the material world – how we create the things required for human survival, both as a technical and social process - to be a product of human consciousness, ideology and culture. According to Hegel, "the internal development of Spirit [mind] manifests itself in concrete reality" (Malik, 2014, p.221). At any time, according to Hegel's theory, there are differing ideas which both depend on, and interact with, each other. It is then the conflicts and contradictions between such ideas that drive any material change in society.

Marx switched this relationship on its head to explain the historical development of societies in materialist, rather than idealist, terms. So rather than human consciousness, what Hegel called 'Spirit', creating the material world, Marx argued that the historical development of consciousness, ideology and culture is a result of the way we interact with that material world. He explained this as follows:

In the social production of their existence, men inevitably enter into definite relations, which are independent of their will, namely relations of production appropriate to a given stage in the development of their

material forces of production. The totality of these relations of production constitutes the economic structure of society, the real foundation, on which arises a legal and political superstructure and to which correspond definite forms of social consciousness. The mode of production of material life conditions the general process of social, political and intellectual life. It is not the consciousness of men that determines their existence, but their social existence that determines their consciousness (Marx, 1859, p.2).

Within this analysis, the mode of production refers to "the social activity and the social relations through which human beings interact with nature in producing the conditions of life" (Meiksens Wood, 1995, p 26), in other words how a society produces and reproduces itself. The mode of production consists of both productive forces and the relations of production. The term productive forces refers to all that is involved in producing what is required and relations of production refers to the social relationships between these components. It is then the dialectical relationship - the conflicts and contradictions which tend to produce change (thesis – antithesis – synthesis) - between these which both produce the consciousness, ideologies and cultures within a society and which also drive and create material change in society.

One potential criticism of historical materialism is that it is too simplistic and can lead to economic determinism where the mode of production is viewed as the only determining factor in how a society operates and changes. However, as Engels (1890) clearly stated, to conclude from this analysis that the economic element – the mode of production – is the *only* determining factor misunderstands the dialectical relationship and reduces history to a simplistic equation which is both meaningless and does not give an understanding or insight to anything. The point is the mode of production is the ultimately determining factor, but consciousness, ideologies and cultures "also exercise their influence upon the course of the historical struggles and in many cases preponderate in determining their form. There is an interaction of all these elements in which, amid all the endless host of accidents…the economic movement finally asserts itself as necessary" (Engels, 1890, no pagination).

Meiksens Wood (1995) argues for the importance of understanding the mode of production as being a "social phenomenon" (p.65). Indeed, at the end of the previous quote from Marx he refers to it as being our "social existence", so for example the mechanism for the extraction of surplus value creates the social relation between appropriator and producer, between capital and labour. This allows again for a more comprehensive understanding of historical materialism.

Whilst ideology can have an impact on the mode of production it is crucial, therefore, to understand how that ideology itself relates to the mode of production. Simply trying to change consciousness without understanding that consciousness in relation to the mode of production will fail to bring about lasting and substantial change. For example, addressing prejudicial attitudes towards disabled people is important in fighting oppression, but is not enough to actually bring about a change in the material reality and conditions of disabled people under capitalism. Moreover, since it is these material conditions which drive the prejudice disabled people experience these conditions must be changed in order for challenges to these attitudes to be effective.

All of this means that a historical materialist explanation of how disability is produced requires an understanding of its relationship to the mode of production. There is much debate about how the policy category of disability was constructed and how people with impairments were viewed and treated prior to capitalism becoming the dominant mode of production (Stone, 1984; Gleeson, 1997; Oliver 1990). However, this research is interested in how it was produced and is reproduced under capitalism.

Capitalism depends on people being compelled to sell their labour power in order for it to function (Priestley, 1997; Meiksens Wood, 2002) and this compulsion is done by the relations of the mode of production under capitalism requiring people to sell their labour power in order to access the means of subsistence. The rise of industrial capitalism had a direct impact on people with impairments as it saw a "rise of mechanised forms of production" and "introduced productivity standards which assumed a 'normal' (viz, usually male

and non-impaired) worker's body and disabled all others" (Gleeson, 1997, p 196). This meant that "as production became industrialised people's bodies were increasingly valued for their ability to function like machines" (Russell & Malhotra, 2009, p 213), which means anyone who cannot labour to this standard is of less value and more likely to excluded from the labour market. However, this devaluation is not confined to the stage of capitalism which required hard physical labour. Chapter 2 will examine recent developments in the nature of work and whether they mean that people with impairments continue to be at a disadvantage, thus confirming Abberley's prediction nearly twenty years ago:

> With accelerating technological change and the globalisation of markets, for the less skilled future prospects of stable employment look bleak, whilst for those possessing qualifications three or four career changes in forty years do not seem unlikely. Both of these tendencies make the prospects of inclusion in the permanent labour force, and consequent citizenship more problematic for disabled people. As technological advances and increased globalisation combine to make permanent employment an increasingly rare phenomenon for the majority of the workforce, disabled people will continue to be in the forefront of those groups who cannot provide the versatility and work rates demanded by the labour market (Abberley, 1999, p.11).

It is not necessarily the type of labour required which results in disabled people's social exclusion, as people with different impairments will find different types of labour more or less difficult. The key is that the focus on individual labour power means there is a social evaluation of work which results in those who are in any way less productive or flexible being devalued (Gleeson, 1997). This means that, regardless of the type of labour required, if someone has difficulty selling their labour this creates a group of people who are viewed as a social problem. Unless this social problem is understood as arising from disabled people's relationship to the mode of production it results in an individual's impairment being viewed as the problem - rather than the mode of production being the problem.

A focus on impairment is the foundation of what Oliver (1983) calls the individual model of disability. This model of disability examines impairment from an individual perspective and concludes it is a problem located in the individual that creates any barrier to their participation in society – whether this be waged labour, education, or any other social activity. This is therefore assumed to require a solution aimed at how an individual's body or mind functions, usually meaning a focus on the role of medical and scientific experts to cure or 'fix' the individual. It was this cultural representation of impairment which created the segregation of disabled people and was ultimately the rationale behind eugenics, where some people are seen as biologically inferior and acting as a drain on society and human development (Russell & Malhotra, 2009).

1.2 Historical materialism and the social model of disability

The social model grew out of a critique of this individual model and has its origins with an organisation of disabled people in the UK called UPIAS (Union of the Physically Impaired Against Segregation). The formulation of the social model and the foundation of UPIAS was a direct result of failure to understand the material reality of a group of disabled people living in an institutional home, Le Court in Hampshire. Researchers referred to the role of the staff within this home as facilitating residents' time from social death to physical death (Finkelstein, 1991) and the residents' to be passive recipients of care. In contrast, the residents believed that they were best placed to understand how and in what ways staff could support them and what was in their best interests. However, as Finkelstein (1991) notes:

> The idea of residents controlling the management of an institution in which they lived seemed to conflict with the very essence of why they were there in the first place – i.e. placed in 'care' because they cannot control their own lives and function independently in the community (p 1).

This lack of autonomy and control over their own lives is something that is a continuing battle for disabled people, including as we shall see, in the context of their experiences of out-of-work disability benefits.

This thesis uses an understanding of the terms impairment and disability which is grounded in the social model of disability. The social model has at its center the separation between what is understood as impairment and what is understood as disability. In their publication 'Fundamental Principles of Disability' UPIAS stated:

> We define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities (UPIAS, 1976, no pagination).

This meant disability was seen as:

> something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society (Ibid).

This social oppression is therefore viewed as the experience of disabling barriers which prevent people with impairments from full participation in society.

The social model of disability can be seen to be compatible with a historical materialist analysis. Instead of viewing disabled people's social experiences as the result of their impairments, disabled people's oppression is viewed as being a result of their relationship to the mode of production (Finkelstein 2001; Gleeson, 1997; Oliver 1990; Russell 2001). However, it must be recognised that the social model is not a "monolithic entity, but rather as a cluster of approaches to the understanding of the notion of disablement" (Lang, 2007, p 2) and as such there has been much debate and contention about the source and cause of this oppression, with some placing more importance on ideology and ideas – which, if we return to Hegel's analysis of history and social formations, is essentially an idealist understanding (Priestley, 1998; Sheldon,

2005). An idealist approach recognises disability as a form of oppression and argues that changes at a cultural level (challenging prejudice and discrimination) are required to overcome the social and economic disadvantages faced by disabled people.

In contrast, a historical material analysis would argue that, whilst culture and ideas play an important role in disabled people's oppression, these cultures and ideas are directly related to, and a result of, the mode of production within a given society. It is also noted by Sheldon (2005) that, although an idealist approach can improve the material conditions for some disabled people – by challenging discriminatory attitudes and behaviour by, for example disability equality training, media representation or rights based legislation – this only addresses the symptoms and not the cause of disability (see also Russell & Malhotra, 2009). As Gleeson (1997) argues, "dematerialising" the explanation of disability results in a failure to understand how these attitudes, ideas and cultures are formed.

> The view of disability as an attitudinal structure and/or aesthetic construct avoids the issue of how these ideological realities are formed. Idealist prescriptions are consequently reduced either to the ineffectual realm of 'attitude changing' policies or the oppressive suggestion that disabled people should conform to aesthetic and behavioural 'norms' in order to qualify for social approbation (p.184).

However, as previously mentioned, some critics of using a historical materialist analysis claim that it is a reductionist argument which places too much importance on economic factors. For example, Armer has argued that "there is no inherent economic, or 'market', bias against the employment of people with impairments per se" (Armer, 2004, no pagination). This infers that it is attitudes and ideas which are to blame for creating the discrimination people face finding jobs, rather than the material reality of the labour market. Part of the rationale for this argument is that advances in technology and changes in the types of jobs in the UK labour market mean there has been a reduction in the physical demands of work, producing more work options for people with physical

impairments – something some historical materialist disability activists also believed would happen as technology advanced and thus changed certain aspects of the mode of production (Finkelstein, 1980). However, as will be discussed in Chapter 2, while the shift from a predominantly industrial labour market to one dominated by service industries may have reduced the number of heavy manual labour jobs, it has not necessarily reduced the physical or mental demands on workers. Instead, it has produced new and different physical and mental demands, which are reflected in the changes in the main reported impairments of those claiming out-of-work disability benefits.

Another criticism of the social model has been about how it views and accommodates different impairments. The definition of impairment and who is considered a disabled person has shifted over time - from both the point of view of the administrative categorisation of disability (see below) and that of the disability movement. At the time of the activities of the residents of Le Court and the foundation of UPIAS, theorising about disability and disabled people's oppression was mainly focused on people with physical impairments. Over time the category of impairment (as understood using a social model approach) has broadened significantly, and this broadening has also occurred within the administrative categorisation of disability and accompanying validating devices (see below). In other words, it is often tied to requiring and obtaining different forms of state support or recognition of an impairment. This social construction of disability is something which will be discussed in the final section of this chapter in relation to the concept of validating devices used to determine who is eligible for state support. The next section of this chapter deals with the tensions regarding the ability of the social model to be applied to different impairment groups.

1.3 The social model of disability and people with long-term health conditions

There has been concern that the social model fails to accommodate some experiences of impairments, particularly people with long-term health conditions. As the Note on Terminology explained, mental health conditions are included as part of this group, which as we shall see is increasingly the largest

group of people claiming out-of-work disability benefits. The potential exclusion of people with long-term health conditions from a social model analysis is particularly an issue if a social model understanding is reduced to arguing that it is only environmental and attitudinal barriers - barriers created by society - that prevent disabled people from working and participating in society in general.

Such concerns are borne out of accusations that the social model, with its focus on disabling barriers, fails to take adequate account of people's experiences of their bodies and minds. As this research will also show, many disabled people believe that it is these functional restrictions that are the main barrier to them working, rather than the type of external barriers that the disability movement has traditionally focused on. This has often led to tensions and suggestions that the social model is not useful for people who have chronic or mental illnesses. The feeling of exclusion by those who are chronically ill is, for example, clearly expressed by disability activist Hale:

> The fact that our exclusion from work and society stems more from our impairment than from externally imposed disability makes us feel we're not proper Disabled People and that the social model of disability is not for us (Hale, 2015, no pagination).

However, it has been well argued that the social model is not a theory or hypothesis (Finkelstein, 1996). Instead it is a tool used to gain insight into situations which otherwise are difficult to begin explaining, and it has also been argued that the model does not deny the importance of impairment or medical intervention to treat or manage an impairment (Priestley, 1998; Barnes, 2007; Oliver, 2004; Finkelstein, 1997). Indeed, inadequate access to healthcare, and failures to invest sufficiently in research and treatment for specific conditions, are disabling barriers in themselves and their consequences for people's experiences of their bodies should not be denied.

Rather than be excluded from the disabled people's movement it could be argued people who have chronic illnesses are absolutely key to understanding

how the current mode of production disables and discriminates against people and how inadequate the idealist approaches to disability are in addressing these. Even if all the environmental and attitudinal barriers were addressed this would not result in many of those with long-term health conditions suddenly being able to engage in waged employment. Instead it is important to consider the very nature of waged labour within the capitalist mode of production as one of those disabling barriers.

This point is illustrated by the experience of disability activist Kaliya Franklin, who wrote very clearly about how even where an employer both understood her impairment and worked very hard with her to remove all barriers to her working, it still was not possible if she experienced an acute episode in her condition (Franklin, 2015, no pagination). So, is it the very nature of competitive waged labour and its importance in our society which needs to fundamentally change? If waged labour – and with it the current mode of production - was not central to both being considered a valued member of society or indeed to materially survive, then this could relieve some of the disability (i.e. social oppression) someone with a long-term health condition faces.

The next two sections look at two particular concepts which are crucial to understanding how people with impairments who find the mode of production disabling are considered and managed in terms of government policies. These are, firstly the reserve army of labour and secondly, the concept of a validating device.

1.4 The reserve army of labour

The concept of the reserve army of labour is important to this research as it provides a vital insight into disabled people's situation both within capitalism in general, and in the current stage in particular. It was developed by Marx to explain the role of those people who, whilst not currently engage in waged labour, provide a pool of potential labour power that employers could bring into the labour market when required. Marx categorises this as the relative surplus population which represents not just "a mass of human material always ready for exploitation" (Marx, 1867, p.444), but is also crucial in the control of wage

inflation as "the general movements of wages are exclusively regulated by the expansion and contraction of the industrial reserve army" (Ibid). This role of the reserve army in controlling wage inflation and maximising capital accumulation is paramount to the functioning of capitalism and it has been argued that "much of contemporary social policy has to be understood as facilitating this process" (Bryne, 1997, p 27). Government policies which expand and restrict the reserve army act as a mechanism of labour discipline. They both help control wage inflation and compel people to sell their labour power, meaning they are therefore essential to enabling capitalism to function. This is crucial in understanding disabled people's situation in the current stage of capitalism and help give greater understanding to the concepts of the needs based and work-based distribution systems discussed in the next section of this chapter.

The material reality of the experience of impairment in industrial capitalism meant that disabled people formed the very lowest rungs of Marx's reserve army of labour, what he referred to as the "lowest sediment" or "stagnant surplus" of the relative surplus population which makes up the reserve army. He refers to this sediment as "the hospital of the active labour-army and the dead weight of the industrial reserve army" (p.450). However, Stone argues that "the disability concept was essential to the development of a workforce in early capitalism and remains indispensable as an instrument of the state in controlling labour supply" (Stone, 1984, p 179). In other words when labour markets become tighter and the active reserve army diminishes, disabled people find themselves increasingly pushed from this dead weight – the 'stagnant surplus' - into a more active role within the reserve army (Russell, 2001; Grover and Piggott 2005). This means that those who previously were not obliged to sell their labour power will be compelled to compete with those that do. It is not enough though to merely have a larger pool of unemployed people, they must also be close enough to labour market to compete for jobs to be effective in keeping wage inflation down. Chapter 2 examines the different policies governments have used since 1970 to attempt to push more disabled people into this active reserve army and discusses whether the nature of work in the current stage of capitalism means there is a limit to which this is possible.

Disabled people also "face a distinct form of economic discrimination inherent in capitalism, in which the costs of nonstandard (disabled) labour are weighed against standard (nondisabled) labour, and employers discriminate accordingly" (Russell, 2001, p 225). A disabled worker may be viewed as costlier to employ than a nondisabled worker if they require additional working adjustments in order to perform a work task and/or if they are considered to take longer to perform labour tasks than a non-disabled worker (Davidson, 2011). The assumption that many/most disabled people are less productive than non-disabled workers has traditionally been part of most developed countries' policies aimed at increasing employment amongst disabled people (see the review of such policies in 18 different countries by Thornton and Lunt, 1997) and is a widely held belief, as UK Chancellor Phillip Hammond confirmed when addressing the House of Commons in 2017 (Hammond, 2017).

Of course, many disabled people will not actually be less productive or more costly to employ, but they may still experience economic discrimination due to the belief they could be. This could be argued to be an example of ideology or attitudes shaping the material reality. However, the discriminatory attitude is driven by the imperative of capitalism to extract as much surplus value/profit from each worker. So, although it may be a wrong conclusion to make, it is this desire, driven by the mode of production, which ultimately creates the discrimination. This tension between, on the one hand, disabled people being required as active work-ready members of the reserve army and, on the other, the economic disincentives to their employment, is played out through the policies and mechanisms aimed at both pushing/supporting disabled people into employment and determining who is considered exempt from being part of the active reserve army and as such part of what Marx termed the 'dead weight' or 'stagnant surplus' population.

It is this determination of who is considered exempt from the active reserve army that is the subject of the next section of this chapter and which is also central to the concerns of this thesis.

1.5 Validating Devices and the administrative category of disability

The administrative category of disability arose alongside the development of capitalism (Priestley, 1997) and the concept is explored in detail by Stone's work "The Disabled State" (1984). In it she traces the origins of the administrative categorisation of disability back to the development of the English Poor Laws of 1601 which grew out of fourteenth century laws aimed at regulating begging and vagrancy (see also Priestley, 1997). These laws sought to determine who was in 'genuine' need of relief and who was adopting the role in order to be excused from social obligations. These obligations were directly tied to waged work, with officials being required to distinguish between those who are "impotent to serve and those able to serve or labour" (Stone, 1984, p. 35). In Stone's analysis this meant distinguishing between who is expected to be part of what she refers to as the work-based distribution system and who is placed in the needs-based distribution system.

The administrative category of disability therefore determines who would be supported through the needs-based system and who would be required to sell their labour. Gleeson (1997) has criticised Stone's analysis of this redistributive dilemma as being fundamental to all societies, and not just to stages of capitalism. However, as with the debates over disability and impairment prior to capitalism, what is relevant to this research is how the current socio-economic structure creates and reacts to impairment and disability. This thesis will therefore be using Stone's concept of a needs-based system to refer to those exempt from selling their labour power, and work-based system to refer to those who are compelled to. It also ties this together with the previous concept of the reserve army to consider those in the needs-based system to effectively represent the 'stagnant surplus population' and those in the work-based system to be part of either the active labour army or active reserve army of labour. It does need to be noted, however, that there is a potential problem with referring to disabled people who are viewed as exempt from selling their labour power as being in a needs-based distribution system as it could have connotations of dependency and a focus on inability. This then would also locate the problem as being within the individual, rather than disability being a socio-political construct.

As previously mentioned Stone's analysis shows how the administrative category of disability is used to control the reserve army of labour and identify who should be eligible for assistance and exempt from obligations to engage in waged labour. This gives rise to the need for mechanisms to be used, controlled and determined by the governing power within a society to determine who is eligible (Stone, 1984). Stone referred to these mechanisms as "validating devices", a term which is particularly useful when talking about the current assessment process for out-of-work disability benefits and disabled people's experience of and relationship to it. These validating devices also allow us to examine and understand how a society and its socio-economic system views and approaches disability.

Stone argues that, from the early days of vagrancy laws (which went on to underpin the Poor Laws of 1601 and 1834):

> The connection between disability and deception meant that the very category of disability was developed to incorporate a mechanism for distinguishing the genuine from the artificial (p 32).

The validating device thus confers both legitimacy of exemption from waged labour and a social identity of 'deserving' of support. Despite this notion of 'deserving' support it is also important to acknowledge that the Poor Laws were strongly based on the principle of less eligibility which stipulated that those given 'relief' in workhouses had to be at such a level as to act as a deterrent to claiming that relief and as such prevent any undermining of the work-based distribution system. Such an aim is also to be found in contemporary governments' insistence that no one must be better off on benefits than in work (Osborne, 2013). This is yet another way that this administrative category of disability is used as part of the mechanisms for labour discipline within capitalism where people are compelled to sell their labour or, if they 'qualify' via the validating device, to live in relative poverty.

Chapter 3 is concerned with changes in the validating device - in the form of the assessment for out-of-work disability benefits. These changes are examined in the context of both the analysis of labour market developments presented in Chapter 2 and changes in both policy and social attitudes towards who should be exempt from selling their labour.

It should be noted that there are both other forms of administrative categories in relation to disability (see for example Finkelstein, 1991) and indeed other validating devices (for example the assessment for Personal Independence Payment, an additional costs payment which is not related to work status). This research is concerned with how disability as an administrative category works in relation to waged labour and the economy because, as Oliver (1999) argued, the "oppression that disabled people face is rooted in the economic and social structures of capitalism" (p.4). Although the other administrative categorisations of disability and their validating devices are important and contribute to disabled people's oppression, when using a historical materialist understanding these are all interlinked and related to the mode of production. For example, as Oliver (2002) illustrated, the categorisation of disability within education (the definition and identification of 'special educational needs') is directly tied to what is required to produce a productive workforce and gives rise to an administrative category (together with a validating device - the assessment of 'special needs') for those who fail to conform to this standardisation (children with special needs).

1.6 The validating device and disabled people's lived experiences

The concept of a validating device is interesting on a number of levels and raises a number of important questions, the most important of which (for the purpose of this thesis) is: What is this device validating? The device this research is concerned with is, as mentioned above, one which determines whether someone is expected to engage in waged labour and what support they are entitled to receive if they are considered to be exempt. Crucially, because the validating device has, since its inception, been closely tied to ideas around who is considered genuine and deserving, it therefore acts as a form of legitimacy or validation of someone's experience of their impairment

and how this impacts on their ability to engage in waged labour. The device is concerned with validating whether a person has an entitlement to expect support from the State, or whether they have to sell their labour power in order to survive. The question arises, however, as to how close the validating device is to an individual's experience of their ability to sell their labour power and it is this issue with which the thesis is centrally concerned.

Having reviewed and critically analysed changes in the labour market and changes in the validating device, the primary research for this thesis is directed at understanding why the current validating device, the Work Capability Assessment, takes the form that it does (Chapter 5), and also understanding disabled people's experiences of it (Chapters 6 and 7). In so doing, it is interrogating on the one hand how the State defines 'disability' by which in this context is meant incapacity to labour (whether someone is 'fit to work'), and on the other hand how people experience the application of this administrative categorisation of disability (as applied by the Work Capability Assessment). The relationship between how people experience the WCA and how they experience their ability to sell their labour power is a key part of understanding the extent to which the validating device accords with disabled people's lived experiences.

It is important to recognise that a social model approach to the lived experiences of people with impairments is concerned with the disabling barriers experienced across the many different aspects of a person's life and opportunities. In contrast, to a large extent in the context of contemporary capitalism, "Disability itself has come to mean 'unable to work'" (Finkelstein, 1991, p.8) and indeed the operation of the validating device illustrates this. Finkelstein was writing about how "the struggle for greater power over their own lives provided the experience for challenging the prevailing understanding of disability and the development of their own interpretation of their situation" (Ibid). The research for this thesis is concerned with disabled people's "own interpretation of their situation" and this is key to exploring the argument that there is a disconnect between current policy approaches to disability and disabled people's lived experiences. So too is the documentary analysis carried

out in Chapter 5 which seeks to understand the development of the theoretical and conceptual framework of the WCA and why the assessment takes the form that it does. The question then arises as to, if there is a disconnect - in other words if the WCA treats people's self-defined experiences as invalid - whether the validating device is itself a crucial aspect of the social oppression experienced by disabled people.

Conclusion

This chapter has set out the theoretical approach to this research, the focus of which is how changes in eligibility for out-of-work disability benefits are related to changes in the political economy, and the disconnect between the current validating device and disabled people's experiences. It has outlined the importance of three key concepts to this research, all of which are interlinked. Firstly, a historical materialist understanding of the social model of disability, that it is important to understand disabled people's relationship to the mode of production and that it is this which is central to identifying and addressing their oppression. Secondly, the reserve army of labour, its vital role in the function of capitalism and disabled people's relationship to it. And finally, the administrative category of disability and the validating device which determines who is exempt from selling their labour and as such also acts as a control mechanism for the active reserve army allowing it to expand and contract in order to prevent wage inflation, inhibit the power of workers and enact labour discipline. Chapter 2 explores how disabled people were affected by changes in the labour market in Britain since the 1970s, and the extent to which they have been or could be pulled into the active reserve army of labour. Chapter 3 details how the validating device has changed, and the ideas associated with these changes. The current validating device, the Work Capability Assessment, developed out of specific ways of thinking about disabled people and employment and this is explored in Chapter 5. It is the contention of this thesis, however, that these ideas and rationale are both rooted in the material reality of the current mode of production and are profoundly disconnected from disabled people's personal experiences. Those experiences are articulated by the account, in Chapter 6 of the experiences of the Work Capability Assessment, while Chapter 7 seeks to understand the nature of the relationship that is being

played out within this implementation of the validating device. The final chapter analyses the most recent developments in the process of applying for out-of-work disability benefits before looking at whether improvements could be made to the (in)validating device. Some steps are identified which would possibly mitigate the disconnect which has been described and prevent disabled people's self-defined experiences being treated as invalid. However, it will be argued that a historical materialist analysis of disabled people's experiences in contemporary capitalism indicates that more fundamental changes to the current mode of production are required before disabled people's own experiences of their impairment and disabling barriers are not only validated but their relationship to the labour market profoundly changed.

Chapter 2: Remaking 'the dead weight': Disabled people and changes in the labour market

Introduction

This chapter examines changes in the labour market since the 1970s, how disabled people's employment opportunities have been affected by such changes, and assesses the extent to which disabled people are being pulled into the active reserve army of labour (as defined in Chapter 1). The chapter will analyse how British governments' approaches to disabled people's relationship to the labour market have varied over time. It will argue that, during certain periods, large numbers of disabled people were seen as part of the 'stagnant surplus-population' or 'dead weight', and as such in the needs-based distributive system. In contrast, at other times policies have been directed at pushing disabled people into the active reserve army of labour, to be available to fill employers' and capital's requirements, moving them into the work-based distributive system. However, the chapter also raises the issue of whether there is a limit to which disabled people's labour can, in reality, form part of the active reserve army of labour, and if so, whether we have reached such a limit, particularly given changes in the nature of work and the structure of the labour market.

It is the contention of this chapter that governments' concerns with the levels of employment and unemployment amongst disabled people, and how to respond to economic inactivity, are closely linked to the varying demands for labour and to the economic and political consequences of public expenditure. There was a steady rise in the numbers of people claiming out-of-work disability benefits from their introduction in the early-1970s to the mid-2000s when they peaked (as discussed in the next chapter). Despite policy aims to reduce the numbers, at the time of writing (2017) they remain at around the same level. The variation between employment rates of disabled people compared to non-disabled people also rose over this period, with the 'disability employment penalty' - the extent to which a disabled person was less likely to have a job than a non-disabled person - increasing from 17 per cent in 1987 to 28 per cent in 2000

(Berthoud, 2011, p.23) and standing at 31.4 per cent in 2017 (Office for National Statistics, 2017a). This gap has reduced marginally in the last few years, having stood at 33.5 per cent in 2014.

Over the same period the UK economy and labour market have changed substantially. This chapter will examine the link between these changes and disabled people's experiences of employment and unemployment. It will also ask whether one of the reasons for both the increase and apparent difficulty in lowering the numbers claiming out-of-work disability benefits is because work itself has become not only less available but also more disabling and hostile to those with impairments and/or long-term health conditions. This is an argument which is key to the thesis of disabled people's contested experience in the context of the administrative category of disability, in the sense of there being a disconnect between their lived experiences and the rationale of the validating device. The following chapter will examine changes in governments' policies on out-of-work disability benefits and the political ideology associated with such policies. This chapter is concerned with the material context of such changes and will also focus on the increasing concern that governments have had with disabled people's 'employability'. It will argue that these concerns are an illustration of how fundamental changes in the economic structure of Britain in the late 20th and early 21st century have profound implications for governments' approaches to both out-of-work benefits and disabled people's employment.

2.1 'Remaking the nation's labour force'

The immediate post-Second World War period in Britain was characterised by Keynesian economics with significant government intervention in industry to rebuild the economy, developing and investing in public services, and increasing employment with high levels of trade unionisation. Governments' approach to the labour market during this time has been characterised as a "guardian" strategy, of "indemnifying workers and protecting jobs" (Robertson, 1986, p. 276). As far as economic and social policy was concerned, there was a general acceptance during the 1950s, 1960s and into the 1970s that it was legitimate that governments develop policies which sought "to insure a job or surrogate income as a right of citizenship" and to provide "those who cannot

compete in the labour market with a safety net of income guarantees"
(Robertson, 1986, p.277). The policy of full employment as an essential part of
Keynesian economics and a key aspect of Beveridge's vision (see for example,
Harris, 1977), together with an economy dominated by full-time and relatively
secure jobs, "meant that the fiscal base of social insurance systems….was
generally sound" (Byrne and Ruane, 2017, p.5). This was a time of expanding
social protection and from the end of the second world war to the end of the
1970s, "social inequality was at its lowest level ever" (Ibid., p.6).

2.1.1 Guardianship and exclusion

The Tomlinson Report on the "resettlement and rehabilitation of disabled
people", published in 1943, reflected a similar 'guardian' approach to disabled
people's employment, stating that they should be afforded "their fair share
within their capacity of such employment as is ordinarily available" (para. 71a).
However, while during the war, about half a million disabled people had been
drafted into the workforce (Humphries and Gordon, 1992) – as the military draft
saw a severe contraction of the labour force and required many who had been
considered outside of the work-based system to be pulled into it - during the
post-war period they tended to be relegated back to the margins of the
workforce as the labour supply increased with those returning from the war
(Thornton and Lunt 1995). This was despite the fact that the 1944 Disabled
Persons (Employment) Act required larger employers to employ 3 per cent of
registered disabled people as part of their workforce, and also set up a
specialised employment placement service, and assessment, rehabilitation and
training services. Such provisions were, however, poorly implemented and had
limited coverage being primarily focused on people with acquired physical
impairments, particularly aimed at those injured during the war, with an
emphasis on rehabilitation and enabling them to take on low skilled manual
jobs (Barnes, 1992). Large numbers of disabled people were excluded from
mainstream employment (Brown, 1990) and to at least some extent from
society in general, what some researchers called "a social death" (Finkelstein,
1991, p.2). Many were assumed to rely on "medical and rehabilitative
treatment, backed up by dependence on family and friends for assistance

and/or a safety net of welfare benefits and services" (Barnes and Mercer, 2005, p. 528).

It could be argued that this widespread exclusion from the labour market meant that disabled people were generally in the category of people designated within Marx's analysis as the 'dead weight' or 'stagnant surplus' of the surplus population and as such were largely seen as part of the needs-based distributive system. At the same time, the fact that - when labour was scarce during the Second World War - a significant number of disabled people had been pulled into the workforce (as documented by Humphries and Gordon, 1992), indicates that when economic conditions require it people who have previously been considered unemployable become part of the active reserve army of labour that employers will utilize, pushing them into the work-based distributive system.

2.1.2 The neoliberal revolution and restructuring of the labour market

Following the break-up of the Bretton Woods agreement – which had seen fixed exchange rates for trade and investment – and the oil crisis in the early 1970s, the UK entered a period of recession and stagnation. The result of these developments globally also saw the beginnings of the increasing movement of capital, goods and labour between countries at various stages of industrial development. As Streeck argues, most Organisation for Economic and Co-operative Development (OECD) countries saw:

> a neoliberal revolution which began in the 1970s and essentially abolished the 'mixed economies' of the three post-war decades, resulting in a more or less continuously growing role of markets, including international markets, in political-economic governance (Streeck, 2013, p.1).

This neoliberal revolution has also been described as "a return to ordinary capitalism" (Schram, 2015) after the 'abnormality' of Keynesian capitalism, which believed that government intervention was required to protect economies and workers from the cyclical crises of capitalism whereby supply would outstrip demand and result in mass unemployment and falling profitability. Neoliberal capitalism on the other hand views the markets as the best way to

produce economic growth and determine the distribution of resources. The state's role is to facilitate markets where they exist, by for example promoting a flexible labour market, and to create them where they do not (Harvey, 2005), by for example outsourcing assessment for benefits to private companies. This creates a state where instead of social protection "offers 'opportunities' and 'choice' to 'customers', who in return must shoulder a greater degree of responsibility for their individual predicament" (Rutherford, 2007). It "most fundamentally is about making economic rationality the basic ethic for everyday living in all areas of life" (Schram, 2015, p 23). All of which has had a direct impact on the development of out-of-work disability benefits and their accompanying validating device.

From the mid-1970s there was a significant shift in the nature of the British economy and its labour market, beginning with a decline in manufacturing industry, and an opening up of financial and service industries. This shift is reflected "in a 'redistribution of work' from older men to women of all ages, from heavy industry to service jobs, from full-time jobs to part-time, from old industrial regions to new centres of economic growth, and so on" (Macnicol, 2013, p.34). Between 1981 and 2006 the proportion of manufacturing jobs declined from 31 per cent to 17 per cent (men) and from 18 per cent to 6 per cent (women), banking and finance increased from 11 per cent to 21 per cent (men) and 12 per cent to 19 per cent (women) (Ibid).

The decline in jobs in the more traditional manufacturing industries had a disproportionate impact on unemployment rates in different parts of the country, but it was also reflected in higher out-of-work disability benefit claims in the regions suffering the highest job losses (Beatty and Fothergill, 2013). Jobs in these areas were dominated by skilled and unskilled manual occupations and both the unemployment and the economic inactivity rate amongst these occupations increased between 1979 and 1993 (Bartley and Owen, 1996). The economic inactivity rate rose more significantly between 1979 and 1993 for men in manual occupations with limiting longstanding illness than it did for men in non-manual occupation and by 1993, it was evident that "a man has to be 'healthier' to remain employed in a manual rather than in a managerial, professional, or clerical occupation" (Ibid, no pagination).

As we shall see, this disparity remained even when unemployment rates fell significantly, and some politicians and commentators argued that high disability benefit claims in these areas during the 1980s masked 'hidden unemployment' (Beatty & Fothergill 1994). This issue is discussed below, but it could also be argued that the decline of heavy industries in certain parts of the country meant that workers previously employed in them now entered what Marx called the stagnant surplus-population and that recognition of their eligibility for out-of-work disability benefits was confirmation of this status. This, as chapter one discussed, also reflects Stone's analysis of the administrative category of disability being a flexible mechanism which can be contracted and expanded relative to the needs of the work-based system, which, as Russell has argued, essentially means to the needs of capital (Russell, 2001).

At the political level, increases in unemployment were treated as necessary to both facilitate industrial restructuring and bring down inflation (which peaked at over 25 per cent during the 1970s). This resulted in policies which sought to bring about "a workforce that is less organised, has greater wage disparities, and is more adaptable to business needs" (Robertson, 1986, p.298). Soon after she became leader of the Conservative Party, Margaret Thatcher had signalled that a government led by her would seek to take action to reconfigure British industry:

> Difficult though it may be, we must strike a balance between the heartless policy of adding to a pool of unemployment when a firm runs into financial difficulties, and the mindless policy of never having men and women available to move into tomorrow's jobs (Thatcher, 1975, no pagination).

This signalled a break with post-war governments' commitment to full employment and an acceptance that an increase in unemployment – and with it an increase in the reserve army of labour - was necessary in order to control inflation and reconfigure British industry. An increase in unemployment was also accepted as necessary in order to break the strength of the trade unions who were seen as a significant barrier to re-modelling the economy, both in terms of a shift from an industrial manufacturing economy to a service and

financial services-led economy, and a shift from long term secure labour contracts to short term more flexible contracts which placed more control in the hands of employers (see further discussion below).

2.1.3 The 'active' state

When the Conservative Party came into government in 1979, Margaret Thatcher adopted a position which, as Robertson (1986) identifies, combined neoliberal economics with an active state. Although the Thatcher government was:

> ideologically suspicious of social security, they recognised the need for it to 'take the strain' of their attempts to squeeze out inflation, liberate market forces, and cut costs in other parts of the public sector (Sloman, 2017, p.4).

The increase in social security spending associated with labour-market restructuring and the resulting increase in unemployment was therefore tolerated to cushion the impact (Ibid., p.6). However, there were a number of contradictions in public policy approaches which arose during the late 1970s and have continued during succeeding decades. The dominant belief is that the control and reduction of public expenditure is "an essential part of the monetary cure for inflation", as stated in the 1979 White Paper on Public Spending, which began by claiming that "public expenditure is at the heart of our current difficulties" (quoted in Gamble, 1994, p.110). This has coincided with trends that have created significant upward pressures on public expenditure: governments' commitment to low taxes have co-existed with increasing demands on public services, particularly the National Health Service; and the increasing cost of the social security budget as a result of the increasing cost of pensions (for demographic and political reasons), the increasing cost of housing benefit (following deregulation of the private rented sector and reduction in council housing) and the increasing costs of tax credits (because of the downward trend of real wages). All of this is an important backdrop to the increased attention that governments from the early 1990s onwards have paid

to expenditure on out-of-work disability benefits, as discussed below and in the next chapter.

The economy started to recover when the value of the pound dropped after Britain left the Exchange Rate Mechanism in 1992 (fuelled by the increase in exports) and unemployment fell year on year until 2008. However, the nature of the economy was profoundly changed. By the end of the 20th century, the process of globalisation - the free movement of capital, goods and services - had brought about a significant shift of industrial production to China and the global South (Byrne and Ruane, 2017, p.13). In Britain, these developments were accompanied by significant changes in the tax base which, combined with a neoliberal approach to public deficits, created a continuing pressure to cut levels of public expenditure during the last quarter of 20th century, pressure which has increased in the last ten years and which is discussed further below. While the financial crash of 2008 and the resulting bail out of the banks was followed by significant cut-back in public expenditure, this merely exacerbated the existing pressure created by the long-term trends mentioned above.

The shift from a predominately industrial economy to a predominately financial and service economy should - on the face of it - have led to a less physically demanding labour market and opened up more job opportunities for people with impairments and/or long-term health conditions. Indeed, the employment rate amongst disabled people increased by 10 per centage points to 48 per cent by 2002 (Grover and Piggott, 2005, p.714). However, it had only improved by 1.2 per cent by June 2017, to 49.2 per cent (Brown and Powell, 2018), and the disability employment gap - the difference between the employment rate of non-disabled people and that of disabled people - remains at 31.4 per cent (Office for National Statistics, 2017a). This disability employment gap has been of increasing concern to governments since the early 1990s as will be discussed below.

During the 1980s, the Conservative governments tried to increase employment amongst disabled people, but this was primarily through marketing campaigns and a Code of Good Practice aimed at employers, and 'rehabilitation' initiatives such as that delivered by Adult Training Centres (Barnes, 1991, pp.93-97). In

the 1990s they turned their attention to changing the eligibility criteria for out-of-work disability benefits, replacing Invalidity Benefit (IVB) with Incapacity Benefit (IB) and introducing an All Work Test (as described in the next chapter). The change in criteria centred on a requirement that people could only qualify for out-of-work disability benefits if they were unable to take on any type of employment, rather than just their previous occupation or similar, and this signalled a shift towards stricter requirements about being available for work.

However, it was the New Labour governments of 1997-2010 which brought about significant shifts in both attitudes towards and policies on disability benefits and disabled people's employment and Chapter 3 explores how this was the period during which a fundamental shift occurred in governments' approaches to out-of-work disability benefits. Grover and Piggot (2005) make a convincing case that when New Labour came into office in 1997 they pursued policies which sought to increase the size of the active reserve army of labour by bringing groups such as lone parents, the long-term unemployed and people on Incapacity Benefit 'closer to the labour market'. Chancellor Gordon Brown stated:

> The more our welfare to work reforms allow the long-term unemployed to re-enter the active labour market, the more it will be possible to reduce unemployment without increasing inflationary pressures (Brown, 1999a, no pagination).

Such policies were directly linked to the desire to control inflation: as Brown stated, "a clearly defined inflation target" was a key part of his aim of breaking "the old, familiar cycle of boom and bust" (Brown, 1999b, col. 883).

Grover and Piggot (2005) point out that people on long-term sickness and disability benefits were now defined as part of the "effective labour supply" (p.712), with policies increasingly aimed at pushing them from the 'stagnant surplus population' into the active reserve army of labour. This saw the Labour government pursue with greater vigour a three-pronged approach started under the previous Conservative government: embedding an expectation within the benefit system that people should make themselves available for employment and increasingly tying eligibility to participation in programmes which are

intended to increase 'employability'; 'making work pay' by subsidising low wages through the tax credit system; and attempting to influence employer behaviour by disability discrimination legislation first introduced by the Conservative government in 1995 but improved and given more emphasis on implementation after 1997, and by subsidising additional costs to employers through the Access to Work programme.

Nevertheless, the numbers of people claiming IB continued to rise - peaking at 2.7m in 2003 and have plateaued since then, remaining at 2.4m in 2017 (Department for Work and Pension, 2017a). All governments since the early 1990s have committed to reducing the disability employment gap but have so far failed to make significant progress towards this aim. The 2016 Green Paper committed to halving the gap by 2020, a commitment that had been in the Conservative Party's manifesto for the 2015 election (Department for Work and Pensions/Department of Health, 2016, p.6). However, when the following White Paper was published in 2017 the government seemed to have recognised the difficulty in achieving this aim and the 2016 commitment was replaced by a target of getting one million more disabled people into employment within 10 years (Department for Work and Pensions/Department of Health, 2017, p.8). The question arises, however, as to whether even this policy aim is at odds with the material reality facing large numbers of disabled people in the current stage of global capitalism.

2.2 The material reality facing disabled people in the labour market

A number of factors can be identified which help to explain disabled people's experiences in terms of their employment status, some of which support the idea that disabled people can be pulled into the active reserve army of labour when economic conditions require, while other factors will arguably create significant obstacles to the aim of reducing the numbers on long-term out-of-work disability benefits (the 'stagnant surplus population') and the disability employment gap. These factors fall into three main categories: variations in the demand for labour; the ability of employers to 'hire and fire'; and changes in the working environment. These are explored below.

2.2.1 Variations in the demand for labour: 'Hidden unemployment' or 'hidden sickness'?

Although many of those in the older industrial areas who had accounted for the large increase in out-of-work disability claims during the 1980s and early 1990s were, by the late 1990s/early 2000s, now claiming the state pension rather than out-of-work benefits, these same areas still saw a high number of claimants. More than 20 years after the major job losses which occurred as a result of the decline in traditional industries such as mining, steel-making and ship building, the areas where these industries were concentrated continued to experience higher levels of unemployment in general and lower levels of employment amongst disabled people than London, the South East and the East of England (Riddell et al, 2010, p.9). The levels of out-of-work disability benefits claims also remained higher in these areas:

> men are particularly likely to be claiming IB/ESA in areas of the country where there has been long-term industrial decline, such as the Welsh Valleys, the North East, the North West and Glasgow and the west of Scotland. For example, while on average 7.1 per cent of the GB population claims IB/ESA, in Merthyr Tydfil and Easington, 18 per cent of the male working-age population claim this benefit..… by and large, claimants remain concentrated in certain parts of the country (Riddell et al, 2010, p.18).

This regional concentration had been identified by some commentators and politicians during the 1990s as 'hidden unemployment' and this continued to be a common explanation, with the House of Commons Work and Pensions Committee in 2003 stating "We believe that a substantial number of the 2.7 million incapacity benefits claimants do represent hidden unemployment" (quoted by Grover and Piggot, 2005, p.709). The greater risk of economic inactivity amongst men in their 50s and early 60s in these areas also prompted some to argue that the incapacity benefit system, combined with occupational pension arrangements in the event of ill health, provided a 'disability route' into early retirement (Blundell, 2002).

In defining IB claimants as the 'hidden unemployed', the political focus was on individuals' lack of motivation to take up paid employment and the identification of a 'dependency culture', as discussed in the next chapter. Nevertheless, the evidence suggests that there was and is a high correlation between poor health, mortality and receipt of out-of-work disability benefits (Bambra and Smith, 2010, p.76). Rice et al (2006), using data from 12 waves of the British Household Panel Survey, found that the impact of ill health was greater than financial incentives for early retirement, while Kemp and Davidson (2010) looked at the experiences of Incapacity Benefit claimants in the year following their claim and concluded that ill health or impairment was both the main reason why people left work in the first place and was also the key barrier to returning to work.

There is also convincing evidence that employer behaviour is a significant factor in regional variations in disabled people's employment experiences. What evidence there is on employers' attitudes towards employing disabled people tends to suggest they generally believe that disabled people are less productive than non-disabled people (Hasluck, 2006). Where employers have a large pool of labour to draw on, they have little incentive to make adjustments to workplaces or working conditions in order to accommodate someone with impairment or long-term health condition. In contrast, in areas where there is a surplus of jobs, sick and disabled people will find it easier to find employment because employers in these areas are more likely to make adjustments to accommodate their health problems and/or barriers associated with impairment as they have fewer workers to choose between. An analysis of Glasgow's labour market and the numbers of people on out-of-work disability benefit found, for example, that the latter only started to fall after the unemployment rate had fallen and the labour market had tightened: "only after most of the unemployed had been drawn into employment did the long-term sick start to benefit from the city's recovering economy" (Webster et al, p.114). More recent labour force analysis confirms that disabled people's employment rate is correlated with regional employment rates: 42 per cent of disabled people are employed in the North East of England compared with 55 per cent in the South East where there is a lower unemployment rate in general (Rahman, 2016).

Employers' incentives to make adjustments for disabled workers - in order to recruit the labour they require - are likely to be an important factor in the regional variations in levels of employment amongst disabled people.

Far from sickness benefit claims being disguised or hidden unemployment, it has been argued that it is ill health amongst people who are in employment that is hidden and unacknowledged. Minton et all repeated Bartley and Owen's (1996) cross-sectional analysis of occupation, employment and economic inactivity for the period of 1973 to 2009 and concluded:

> During periods of recession, people in poorer health are more likely to lose their jobs than are those in better health, as well as being more likely to have difficulty finding new jobs. Although their health may have been so poor as to make them eligible for incapacity benefit even when they were working, it was only once they lost their job that this latent health problem became realised as a (legitimate) claim for incapacity benefit as they faced a choice between a lower rate as an unemployed person or a higher rate as an economically inactive person (Minton et al, 2012, no pagination).

As Beatty et al (2000) argued, there is a level of ill health amongst the employed workforce which only gets recognised once someone loses their job and they enter the benefit system because they meet the eligibility criteria for out-of-work disability benefits. It was and is still the economy that drives the high levels of claims in parts of the country which lost many jobs during the 1980s, and far from disability benefits being used to hide unemployment, the greater job opportunities in other areas of the economy are masking sickness levels in those areas (Lindsay et al, 2015, pp.7-8).

Disabled people thus bear the main brunt of high unemployment rates in areas of economic decline and stagnation: as Richard Berthoud concludes:

> disabled people have always been more disadvantaged in regions with persistently high unemployment rates. Almost the whole of regional variations in the availability of jobs is born by disabled people, with non-

disabled people enjoying consistent prospects wherever they live (Berthoud, 2011, p.50).

A convincing argument can therefore be made that regional variations in the demand for labour are a significant factor in determining disabled people's experiences of employment and unemployment.

The notion of 'hidden sickness' amongst those in employment would tend to support the idea of disabled people as, potentially, part of the active reserve army of labour, in that, in a tighter labour market, employers will be more willing to draw them into their workforce, if necessary making the adjustments required to enable them to work. In contrast, where employers can meet their labour requirements without incurring the costs of adjustments or lower productivity then disabled people will remain part of the 'stagnant surplus-population' and within the need-based distribution system. This will only hold true of course as long as the validating device is designed in such a way as to recognise experiences of impairment, illness or disabling barriers - a point which will become clear when examining recent and current developments in the validating device.

2.2.2 The impact of a 'flexible' labour market

Also of significance for disabled people's experiences of the labour market is governments' implementation of policies aimed at promoting a 'flexible' labour market - a term which generally refers to the ease with which workers can be hired and fired. From the 1980s onwards legislation reduced employment protection, making it easier for employers to fire workers. Collective bargaining reduced significantly during the 1980s and trade union membership declined, partly as a result of the increase in temporary and part-time employment (Towers, 1989). Increases in these types of employment also brought about a reduction in entitlement to sick pay. Government economic policy generally aimed to strengthen market forces, and their labour market policies aimed to increase labour market flexibility. Detailed analysis of employer practices found that the government's goal of increasing the ease with which employers could hire and fire workers was largely successful by the early 1990s (Beatson, 1995). While, as the next chapter discusses, the government was arguing that

GPs were certifying people as too ill to work who could in fact work, research at the time tended to indicate that the explanation for the increasing numbers receiving out-of-work disability benefits "lies in the economy as a whole, and in the hiring and firing practices of employers, rather than in a change in the behaviour of individual claimants or their doctors" (Strickland, 1994, p.6).

Fifteen years later, as it became clear that many people continued to find it difficult to regain employment having once moved onto Incapacity Benefit, Kemp and Davidson looked at evidence on what distinguished people who remained out-of-work from those who left the benefit within a year and found that returning to work was closely linked to the willingness of employers to make adjustments such as altering their job content or the work environment, allowing changes to working hours or a phased return to work (Kemp and Davidson, 2010).

Despite the implementation of anti-disability discrimination in 1995, legislative and policy changes promoting labour market flexibility arguably made it less likely that employers would accommodate people's requirements related to ill health or impairment. Employers had more discretion as to how they responded to employees who experienced long-term sickness and a survey of Incapacity Benefit claimants found that a key factor determining return to work was whether the employer was "sympathetic" (Green and Shuttleworth, 2010, p.234). Other research found a widely held view that many employers were likely to target people with health problems for redundancy or forced early retirement (Easterlow and Smith, 2003). Increasingly aggressive performance and absence management policies have been developed in most sections of the economy over the last 30 years, with a trend starting in the 1990s when, as a review of research concluded, employers had become "less accommodating towards employees who may contribute less to productivity than others" (Meadows, 1996).

A comprehensive analysis of disabled people's position in the labour market over the thirty years from 1980 to 2010 concluded that "while employers have become more willing to recruit from the large pool of well-qualified women, they have become less motivated to hire or retain people who combine ill-health with

low skill levels" (Berthoud, 2011, p.52), (although, as discussed later in this chapter, it is not necessarily the lack of skills that is the determining factor in whether a disabled person is likely to find employment). This would tend to indicate that there is a limit to which employers are willing to treat disabled people as part of the active reserve army of labour, particularly where there are other groups (women in the 1990s, migrants in the 2000s) who can be pulled into work when the labour market tightens. For example, in recent years Labour Force data indicate that a significant proportion of the growth in employment came from people born abroad and that disabled people were not being pulled into the labour market as the demand for labour grows (Office for National Statistics, 2017c). While the supply of migrant labour may diminish following the United Kingdom leaving the European Union it is questionable whether the labour shortfall will be filled by people currently on out-of-work disability benefits, particularly as these jobs are characterised by insecurity and low control/high intensity, features which - as discussed below - make employment particularly difficult for people with impairments and/or long-term health conditions to fulfil.

2.2.3 The changing nature of work

There is a convincing case to be made that it is not just the ease with which employers can hire and fire, but also the changing nature of work which has made it harder for disabled people to compete in the labour market and, even if they get a job, to sustain employment. Changes to both the occupational structure and the characteristics of the working environment have created significant disadvantages for many people with impairments and/or long-term health conditions.

Over the last 30 years, education and skills have become more important if people are to sell their labour: "as the economy has been increasingly based on knowledge rather than routine production, new jobs have been created in large numbers in high-skill, high-wage professional and managerial occupations" (Sisson, 2011, p.4). People need to compete not just with other workers within the local economy but also with the increasing competition from highly educated workforces in other countries, "able to compete in terms of price as well as knowledge" (Brown et al, 2010, p.10). Labour Force Survey data over

many years has shown that disabled people are under-represented in these types of occupations.

The increasing importance of skills and qualifications, and the impact on disabled people's employment opportunities is starkly illustrated by the fact that, whereas in the mid-1970s, more than three quarters of disabled people with no qualifications were in employment, by 2003 this had declined to a third (Riddell, et al, 2010). The 'skills gap' for disabled people narrowed slightly over the last 20 years but it is still the case that only 15 per cent of disabled people have a degree, compared with around 30 per cent of non-disabled people and more than a fifth of disabled people have no qualifications, twice as many as non-disabled people (Tinson, et al, 2016, p.29).

However, there does not seem to be much evidence of a lack of skills or training being the *determining* factor in disabled people's employment opportunities. At every level of qualification:

> a disabled person is much more likely than a non-disabled person to be lacking, but wanting work – to such an extent that a disabled person with a degree is more likely than a non-disabled person with no qualifications to find her/himself lacking, but wanting work (Palmer, 2010, no pagination).

This would seem to suggest that other factors, such as employer behaviour and the nature of work, may be even more important than what levels of skills or education a disabled person may have.

Nevertheless, changes in the occupational structure and what is required of workers, have had and continue to have significant implications for disabled people's employment opportunities. As Scope's analysis shows, the occupations in which disabled people are over-represented have experienced a decline in recent years and are expected to decline further (Scope, 2016, pp.16-17). This is because changes in the occupational structure of the labour market mean that it has become "increasingly polarized between a core of secure, high-skilled, high wage jobs and a periphery of casualised, low-paid

employment" (Walker and Wiseman, 2002, p.6). This means that the occupations where disabled people are most likely to find work are declining, further diminishing disabled people's ability to sell their labour. The 'hollowing out' of the labour market refers to:

> job polarisation, whereby if jobs are ranked by their initial wage at a point in time in the late 1980s or early 1990s, then increases in employment share are observed at the top and bottom of this distribution, whereas those jobs that were in the middle have lost employment share over time (McIntosh, 2013, p.4).

While this appears to have been going on since the 1980s (Goos and Manning, 2007), technological developments have increased the computerisation of middle-ranking jobs in more recent years. Three quarters of jobs created in the first decade of the 21st century were at the 'top end' of the occupational and wage distribution - in the managerial, professional and technical occupations - while low paid, insecure jobs also increased (Sissons, 2011) but middle-ranking jobs declined. The evidence is that since the recession following the 2007/8 financial crisis, this trend has increased (Plunkett and Pessoa, 2013).

The decline of public sector employment has also had a disproportionate impact on disabled people as they are more likely to find employment in the public than in the private sector. The only occupations where disabled people are over-represented and where job opportunities are increasing is in service, sales and elementary occupations (Scope, 2016, p.18). However, these occupations are also seeing an increase in job insecurity and in high demand/low control factors (discussed below) which impact on disabled people's ability to gain and remain in employment.

Not only do these increasingly common features of employment impact on people who already experience impairment and/or long-term health conditions, but there is evidence that they can create mental health difficulties amongst the workforce. A recent review of well-being and productivity in the workplace summarised research which confirmed that "job insecurity is associated with a doubling of the risk of common mental disorder" (Weinberg and Doyle, 2017, p.6); "high workload' is also associated with high levels of depression" (p.15);

and that "The level of control that an individual has over their work is a key factor for psychological health" (p.6).

Job insecurity had increased for manual occupations since the late 1960s, but longitudinal research found that by the late 1990s non-manual workers were also experiencing a significant increase in job insecurity (Burchell et al,1999). The same research found a significant correlation between job insecurity and poor general health and that people's physical and mental well-being deteriorates the longer they remain in a state of insecurity.

In addition to changes in the occupational structure and increasing job insecurity, disabled people are increasingly disadvantaged by changes in working conditions. Foster and Wass (2012, p. 706) make the valuable point that job design is generally done in a way which has "*abstracted* and *disembodied* the worker from the job, with significant consequences for disabled employees" (their emphasis). Drawing on feminist critiques of the way job design and workplace cultures disadvantage women workers, they argue that "the worker with an impairment is …effectively *dis*abled as a consequence of dominant organisational ideas" (Ibid, p.709). Jobs, they say, are organised on ideas of what constitutes a typical worker and the assumption that this is a (male) worker with no impairment or health condition is "deeply embedded in the practices, policies and culture of organisational life" (p. 716).

These are important general points and accord with the social model of disability, and historical materialist analysis, which underpins the approach of this thesis. There are also specific factors relating to changes in the nature of work which increasingly act as important barriers to disabled people's employment.

For people who in employment are the 'hidden sick' the ability, and the willingness of their employers, to fit their work around their requirements related to their health will be crucial. Yet there is evidence that, as Baumberg argues, the UK has "seen a sharp rise in high-demands, low-control jobs" (Baumberg, 2014, p.290). Although the fall in manufacturing brought about a fall in the physicality of jobs in the British economy, this was not accompanied by a fall in the physical demand in the workplace. A nationwide survey of the experience

of work in the late 1990s found that 60 per cent of employees claimed that the pace of work and the effort they had to put into their jobs had increased over the past five years (Burchall et al, 1999). In fact, OECD research found that Britain experienced the fastest rise in work effort amongst European countries during the 1990s (Green and Macintosh, 2001). It is probably significant that the level of work effort increased the greatest in countries experiencing the greatest decline in trade union membership.

It is not just work effort/job strain which may be making work more difficult for disabled people, but also the extent to which workers can control the pace of their work and their working environment in general. Control enables a person to fit the requirements of a health condition around their job. Yet, as Baumberg points out, OECD evidence found that Britain is unusual in experiencing a rapid decline in job control (Baumberg, 2014, p.293).

The increase in work effort and decrease in control makes it even more likely that jobs will be designed for the ideal non-impaired worker, with no on-going health problems which, as Foster and Wass identified, creates disabling barriers to employment and particularly for employment sustained over a long period of time. It also makes it harder for employers to envisage that adjustments could be made to enable a disabled person to carry out the job tasks, something which Foster and Wass found was apparent when examining the processes and outcomes of Employment Tribunals involving disabled people (Foster and Wass, 2012, pp.712-713).

Baumberg's research tested the hypothesis that work has become more difficult for disabled workers because of increasing intensification and declining control. Modelling average working conditions across a range of occupations he used British Household Panel Survey data to examine the likelihood of starting to claim incapacity benefits and found that people in low-control jobs are more likely to claim incapacity benefits the following year. He concludes that "one sixth fewer people in 2006 would move from work to incapacity benefits if job control had not deteriorated since 1992" (Baumberg, 2014, p. 299).

Not only are more jobs now characterised by low control but the nature of many occupations require a level of resilience which can be hard if someone experiences long-term ill health, particularly mental health conditions. Barnes has argued that:

> whereas in the nineteenth, and most of the twentieth, century an 'able body' was an essential prerequisite for inclusion in the workforce and a 'non-disabled status', so in the brave new world of the twenty first century an 'able mind' may be far more important (Barnes, 1999, p.10).

This may certainly help explain the very low levels of employment amongst people with learning difficulties/disabilities - only about 17 per cent of all people with learning disabilities have paid employment (Mencap, n.d.) - but an 'able mind' also includes resilience and social/iinterpersonal skills and arguably people experiencing depression and/or anxiety disorders will find it particularly hard to gain and retain the increasing number of jobs which require the consistent use of such skills (Deming, 2015). A review of mental health and employment, published in 2017, found that about 300,000 people with mental health conditions lose their jobs each year (Stevenson and Farmer, 2017, p. 19). Only about one in four of people experiencing a long term mental health condition as their primary, or most significant, health issue, are in employment according to Labour Force Survey data. Over time mental health conditions have become the most common cause of benefit entitlement, with the number of claimants rising by 103 per cent from 1995 to 2014 (making up 47 per cent of claims) whereas claimants with other conditions fell by 35 per cent (Viola and Moncrieff, 2016). The most common mental health condition is anxiety and/or depression (McManus et al, 2009), experiences which may make it harder to sustain employment in jobs requiring high levels of social skills and the mental resilience to maintain the relentless 'positivity' required by 'customer-facing' employees (Biggs, 2015).

One final point to be made here concerns how governments in recent years have been promoting the message that unemployment is bad for people's health and that work is beneficial. Indeed, the latest versions of this message, in the 2016 and 2017 Green and White Papers (Department for Work and

Pensions/Department of Health, 2016, 2017) have contended that work is a 'health outcome'. These two publications both drew on a review of work and health carried out in 2006 and which has been referred to by a succession of government Ministers since it was first published. However, that review of evidence also found that, while unemployment was associated with poor health, in order for employment to benefit health:

> account must be taken of the social context, the nature and quality of work, and the fact that a minority of people may experience contrary effects. Jobs should be safe and should also be accommodating for sickness and disability (Waddell and Burton, 2006, p.38).

The importance of such qualifications is confirmed by a recent study which, as well as reviewing evidence which confirmed the importance of the quality of work, analysed new longitudinal data to find that poor quality work can have a bigger detrimental impact on health than unemployment (Chandola and Zhang, 2017). Poor quality work has particular implications for mental health, as found by previous Australian longitudinal research which concluded that "the mental health of those who were unemployed was comparable or superior to those in jobs of the poorest psychosocial quality" (Butterworth et al, 2011, p.806).

In summary, the tighter labour market in recent years (as represented by the fall in the general unemployment rate and increase in numbers employed) has not led to a significant decrease in the disability employment gap: 80.5 per cent of non-disabled people aged 16-64 are in work, in comparison with 49.2 per cent of disabled people (Brown and Powell, 2018). While governments in recent years have frequently quoted figures about how many disabled people have moved into work, this only tells one side of the reality in that it leaves out the question of how many disabled people are leaving work. While a very low rate of unemployment has meant that some disabled people have been able to move into the labour market, analysis of Labour Force Survey data for 2016/17 found that for every 100 disabled people moving into work, 114 leave whereas for every 100 non-disabled people moving into work, 97 left (Scope, 2017). Looking at it another way, the government's own analysis of Labour Force Survey data concluded that "disabled people are twice as likely to fall out-of-

work as non-disabled people" and "are approximately 3 times less likely to move into work than non-disabled people" (Department for Work and Pensions/Department of Health, 2017, p.82).

In the context of the current UK labour market, therefore, there is a limit to which disabled people are moving into the active reserve army of labour and it is questionable whether the aim of halving the disability employment gap by 2020, as stated in the 2016 Green Paper (Department for Work and Pensions/Department of Health) could be achieved. Indeed, the Resolution Foundation (2016) estimated that, in order to meet the target, at least 1.5 million disabled people would need to move into employment and, as mentioned above, the government subsequently stepped back from the commitment.

If the argument presented above is valid then - in the absence of any significant changes to the welfare system (such as the direction of travel indicated by recent changes to the Work Related Activity Group, discussed in Chapter 3) the numbers of people in receipt of out-of-work disability benefits will remain at roughly its current level. Expenditure on benefits, as a per centage of GDP, has increased since the late 1970s, from 8 per cent to 11 per cent, and shows no signs of consistently falling - having increased during periods of recession but then failed to fall back to pre-recession levels (Institute for Fiscal Studies, 2016, p.87). Pensions account for just over 50 per cent of this and demographic pressures mean that the government has little prospect of reducing this call on public expenditure (even if the increase in expenditure could be mitigated by changes to the 'triple lock' on pensions). Other parts of the benefit budget have therefore been targeted in governments' attempts to control spending, with an increasing focus on people in receipt of out-of-work disability benefits, as discussed below and in the next chapter.

2.3 "Work for those who can…."
The next chapter explores the changes in disability benefits policy and the political ideology accompanying them in the period since the 1970s, analysing developments in the validating device. It is important to recognise that these changes took place alongside various attempts to make disabled people

'employable', moving them from the 'stagnant surplus' population into the active reserve army. While the earlier stages of the welfare state 'provided for' disabled people through institutionalisation, subsidised labour (through sheltered workshops such as Remploy), and subsistence benefits, the period from 1992 onwards saw an increasing focus on policies which attempted to reduce the disability employment gap by 'getting disabled people back to work'.

While the Conservative government of 1992-1997 became converted to the idea of anti-disability discrimination legislation, this was very much in line with the neoliberal shift towards individual responsibility, and away from collective obligation, which had been gathering pace since the late 1970s. The legislation had been long campaigned for by disability rights activists, and did represent on one level a victory for civil rights. However, it was also compatible with neoliberal individualism. As Thornton and Lunt point out, the new law relied on the individual to bring a case, and there was no obligation on the employer to develop policies and practices which would increase the numbers of disabled people in the workplace (Thornton and Lunt, 1995, p.1). In addition, as a number of disability activists argued, the Disability Discrimination Act of 1995 assumed that "impairment is the cause of disablement rather than the way society is organised" and "the disabled worker must first demonstrate to an Employment Tribunal that they are in fact 'disabled' under the terms of the Act" (Barnes, 1999, no pagination). This means that, rather than demonstrate they have faced disabling barriers, the individual must demonstrate an impairment.

As mentioned above, the way that jobs and working practices are configured and workplaces organised means that, in order for a disabled person to enter or remain in a job, the employer has to 'fit' someone with an impairment or ongoing health condition into a job, working practices and workplaces which were designed for someone that does not. Moreover, any 'adjustment' that the employer is expected to make must be 'reasonable' taking into account the financial cost and implications for their business. This is an example why it will remain difficult to increase the numbers of disabled people in employment under the current economic system. If employing a disabled person will reduce an employer's profit margin they are unlikely to take on a disabled employee or continue to employ someone who acquires an impairment or long-term health

condition. The fact that this is supported by the very legislation that is meant to tackle discrimination against disabled workers is arguably an indication that this is an accepted norm. This also effectively means "The disabled person's theoretical right to an accommodation is really no right at all; it is dependent upon the employer's calculus" (Russell, 2001, p 90)

The focus on individual responsibility was also apparent in the Conservative, Labour and Coalition governments' programmes intended to increase the numbers of disabled people in employment. Whereas the period after the second world war had seen a general acceptance of the state's responsibility towards some disabled people's employment (for example in the form of the quota system, sheltered employment and rehabilitation services for people with acquired physical impairments), the obligation was now placed increasingly on the individual to make themselves available for work. Governments' aims were, as Thornton and Lunt put it when describing the approach of the 1992-97 Conservative government, to make "the individual competitive" (Thornton and Lunt, 1995, p.35). This meant a focus on supply side factors such as individuals' skills, qualifications and motivation to work. When Labour came into office in 1997, the White Paper published the following year identified the problem as the failure of disabled people and other long-term unemployed groups to exhibit the characteristics required of the 'flexible labour market' (Department for Social Security, 1998). As Russell and Malhotra remark of both the US and UK governments' approaches, disabled people's unemployment was increasingly defined "as one of dependency which the faulty individual on welfare must overcome, not as the structural outcome of an exclusionary market" (Russell and Malhotra, 2002, p.220).

In this context, as the next chapter will explore, the state became increasingly concerned with identifying who is 'fit to work', leading to repeated changes in assessment. These changes were accompanied by a series of welfare-to-work programmes which aimed to bring people 'closer to the labour market'. Soon after coming to office in 1997, the Labour government introduced the New Deal for Disabled People, a voluntary programme for Incapacity Benefit claimants, involving the allocation of a Job Broker whose role was to place people on appropriate training programmes and build links with local employers. The

programme also included an information campaign aimed at changing the 'attitudes' of those in receipt of benefits.

Evaluations of the New Deal for Disabled People generally found that Job Brokers tended to work with the more 'work ready' participants and that they had limited contacts with prospective employers (Cordon et al, 2004) - shortcomings which have been found in most evaluations of the various successors to the New Deal. When the New Deal was replaced by the Pathways to Work programme in 2004, Work-Focussed Interviews were compulsory for all new claimants, signalling the start of the extension of conditionality to receipt of out-of-work disability benefits (Dwyer, 2004). The programme also included "provision aimed at improving labour market readiness and opportunities" (Bewley et al, 2007, p.8), 'condition management' programmes and a variety of in-work support including the possibility of a wage subsidy of £40pw. The various evaluations of Pathways failed to find sustainable impacts on the proportion of people coming off IB and remaining in employment (Bewley et al, 2007, pp.53-55; Knight et al, 2011, pp.35-38).

The Work Programme, launched in 2011 and delivered on a 'payment by results' basis by a range of private and voluntary sector organisations, seemed to do little better than previous programmes. Analysis of results up until 2015 concluded that - like previous programmes - the main beneficiaries were those who were 'job ready' (ie closer to the labour market) and in receipt of Job Seekers Allowance, and that people in receipt of Incapacity Benefit/Employment and Support Allowance were very unlikely to move into sustainable employment (Centre for Economic and Social Inclusion, 2015). Disabled people and people over the age of 50 fared worse than all other groups in the programme (Ibid, Figure 8).

As Riddell et al identify, one of "the consequences of a payment by results regime is that it disincentives engagement with people who are furthest away from the labour market, leading to 'creaming'" (Riddell et al, 2010, p.86). Despite more recent attempts to address this, disabled people facing the greatest barriers (including those who have been on IB/ESA the longest) are the least likely to secure a job outcome as a result of engagement with the

Work Programme or Work Choice (House of Commons Work and Pensions Committee, 2016). Moreover, all these welfare to work programmes tend to aim to get people into 'entry level' jobs, with many on zero hour and/or short-term contracts. This often means working for an agency in industries which rely on outsourcing and sub-contracting and in working environments which people with long-term health conditions will find difficult to sustain, as discussed above. As Grover (2015) argues, an approach that attempts to use market mechanisms (the outsourced Work Programme) to drive disabled people into the labour market "is likely to fail because it is those mechanisms that are responsible for the labour market disadvantage of disabled people".

The various programmes introduced to bring disabled people 'closer to the labour market' have been accompanied by the message, by governments of all political persuasions, "that work is the best route out of poverty for disabled people, as well as for others of working age" (Education and Employment Committee, 1999, p.175). This consistent message is despite the fact that in-work poverty has grown and by 2014/15 12 per cent of all workers were living in poverty (Tinson, et al, 2016). Related to this insistence that work is the best route out of poverty is the contention, mentioned above, that "work is good for people" (Department for Work and Pensions, 2008a, p.11). As already discussed, this claim was made in Waddell and Burton's 2006 review but with qualifications about the nature of work. Nevertheless, a focus on how work is good for health was the main message of the 2016 Green Paper (Department for Work and Pensions/Department of Health, 2016) and the ensuing White Paper of 2017 (Department for Work and Pensions/Department of Health, 2017). Again, this is despite evidence of an increase in the types of jobs which are bad for health (as discussed above) and with little attention paid to whether workplaces and working practices create disabling barriers. Instead, as Grover and Piggott (2010) point out, disabled people are expected to be able to fit in with the working patterns of those without impairment or the experience of ill health.

At the same time, the attempts to increase disabled people's 'employability' have been couched in terms of 'empowering' disabled people, with Labour, Coalition and Conservative governments purporting to adopt a social model of

disability and echoing the language of rights used by disabled people's organisations. This was particularly apparent during the Labour governments of 1997 to 2010. *A New Deal for Welfare* (Department for Work and Pensions, 2006, p.6) promised a "clear framework of rights and responsibilities" while *Improving the Life Chances of Disabled People*, committed the government to the aim that disabled people would achieve equal citizenship by 2025 (Prime Minister's Strategy Unit, 2005).

Alongside these messages governments since the late 1990s have asserted their intention of delivering personalised support to help people 'back to work' and, from 2008, this has been accompanied by "personalised conditionality" (Department for Work and Pensions, 2008b, p.15), in other words the withdrawal of benefits for a period of time if certain conditions are not complied with. This increased conditionality was justified by the belief that benefit claimants needed to be 'incentivised' to seek employment and encouraged to move on from the 'sick role' that they have adopted (a position which is discussed in more detail in Chapter 5, which explores the development of and rationale behind the Work Capability Assessment). Apart from the conditionality which is increasingly applied to those in receipt of benefits, the most recent manifestation of this belief in the need to 'incentivise' disabled people into employment is the reduction of the benefit paid to those in the Work-Related Activity Group (WRAG) of ESA to the same level of Job Seekers' Allowance - a reduction of £30 per week. According to the DWP, this will "remove the financial incentives that would otherwise discourage claimants from taking steps back to work" (Department for Work and Pensions, 2015, p.1).

The latest stage in the state's attempts to move more disabled people out of the 'stagnant surplus' into the active reserve army of labour (see further discussions in Chapter 3) was announced at the end of 2016 with the previously mentioned Green Paper published jointly by the Department for Work and Pensions and the Department of Health followed by a joint White Paper at the end of 2017 (Department for Work and Pensions/Department of Health, 2016, 2017). A commitment to get one million disabled people into work over the next ten years was made, with the main vehicle for doing this to be a new Work and Health Programme. This replaces both the Work

Programme and Work Choice, albeit with only 25 per cent of the funding previously available for the two programmes replaced (Butler, 2017). This programme purports to offer "a more personalised local approach to supporting disabled people overcome barriers to employment targeting specialist support to those who are likely to be able to find work within 12 months" (Department for Work and Pensions/Department of Health, 2017, p. 54). People in the ESA Support Group (those furthest away from the labour market) will be able to access the Work and Health Programme on a voluntary basis and the government is exploring "the potential viability of 'personal budgets' for employment support" (p.24).

It remains to be seen whether these changes to employment support will be any more successful than the previous programmes at enabling disabled people to get into and remain in employment. However, it is the changes to the assessment process which are most relevant to the subject of this thesis. The 2016 Green Paper announced the government's intention of introducing a new stage to the process - that of a Health and Work Conversation - and this is discussed in the concluding chapter of this thesis when considering the future of the validating device.

2.4 'Living within our means'

The changes in the labour market discussed in this chapter took place within a period during which Keynesian welfare state capitalism was replaced by a neoliberal approach of "'workfare state' capitalism in which high welfare expenditure is considered to be incompatible with a growing and profitable economy" (Schrecker and Bambra, 2015, p.16). Government policies and rhetoric have reflected this change in approach with their emphases on individual responsibility, the benefits of working and the need for the country to 'live within our means'. The next chapter will explore the implications for the changes in out-of-work disability benefits since the 1970s, but it is important to understand the wider factors which drove and are driving these developments.

The period of high inflation combined with low growth and recession in the mid-1970s and early 1980s was followed by governments' - both Conservative and Labour - adopting neoliberal economic policies which seek to expand the labour supply in order to achieve economic growth without an increase in

inflation (Macnicol, 2013). In this context, and as mentioned above, the Conservative government of 1979 initially accepted that a high level of unemployment accompanied by an increase in expenditure on out-of-work benefits were necessary to bring about both the structural changes required by the opening up of global markets and the freeing of capital to move production to where labour was cheapest.

At the same time, two key aspects of the impact of globalisation on the British economy - the downward pressure on wages and the ability of companies and highly educated workers to move to lower tax environments - helped to create pressures on public expenditure while at the same time diminishing governments' willingness and ability to raise income to finance public expenditure.

Although the tax and benefits system has included subsidies to low wages since 1971 (when the Family Income Supplement was introduced), expenditure on such subsidies steadily increased during the 1980s and 1990s and almost doubled in the early years of the Labour government when they introduced Working Families Tax Credit, aiming to increase incentives to work (Dilnot and McCrae, 1999). Despite the introduction of a minimum wage and the more recent so-called national living wage, low wages, together with low productivity, remain an important feature of the UK economy (Kumar, 2017). While the introduction of Universal Credit reduces the subsidies on low wages (Child Poverty Action Group, 2017), the continuing need to use such subsidies to 'make work pay' remains a significant pressure on public expenditure.

At the same time, the tax take from low and middle income earners, as a proportion of total tax income, has been steadily reducing since the 1980s as a result of decreases in the basic level of income tax and in the last few years by the increase in personal allowances. This, together with the hollowing out of the labour market mentioned above, has meant that governments have become ever more reliant on taxation income from higher earners (Miller and Pope, 2016, p.6). However, in many respects, these higher earners operate within an international labour market creating pressure for low tax rates and such reliance on a smaller group of taxpayers also makes growth in future receipts "more unpredictable and risky" (Ibid. p.11).

International competition is also seen as a limiting factor on the contribution that corporation tax can make. As Miller and Pope point out, "Corporation tax rates have declined substantially across the developed world since the 1970s as countries have attempted to remain competitive locations for mobile activities and profits" (Miller and Pope, 2016, p. 18). The UK corporation tax rate has been cut in recent years from 28 per cent in 2010 to 20 per cent with a further fall to 17 per cent promised by 2020/21 resulting in a decline in corporation tax receipts. In addition, HMRC estimate that a total of £34 billion in tax is uncollected each year, with £2.7 billion being lost through tax avoidance and £4.4 billion through illegal tax evasion (Full Fact, 2016).

The UK government's deficit increased following the 2008 financial crisis when the debts incurred by banks ended up on the public balance sheet. Neoliberal economics treats public deficits as a fiscal crisis (unlike Keynesian economics) and such an approach was clearly articulated by, for example, David Cameron who, as Leader of the Opposition Conservative Party in 2008, not only echoed Margaret Thatcher's insistence that the country must live within its means (see for example, Thatcher, 1987) but also illustrated the impact of global competition:

> We have reached the limits of acceptable taxation and borrowing' he said. '…taxpayers can't take any more pain. Indeed they want a government that can give them the prospect of relief. And our economy can't take any more pain without losing jobs to lower tax competitors (Cameron, 2008, no pagination).

The Office for Budget Responsibility (2017) warns of an "unsustainable fiscal position…thanks largely to a weaker outlook for productivity and GDP growth, which reduces prospective tax revenues" (p.3). Combined with the increased pressures on public expenditure resulting from an ageing population, the OBR concludes that unless there are tax rises or further spending cuts, this will "widen budget deficits over time and put public sector net debt on an unsustainable upward trajectory" (Ibid).

The continuing impact of globalisation combined with policies informed by neoliberal economics have dominated governments' approaches to public

expenditure in recent years. A desire to reduce expenditure, to 'live within our means', is therefore one of the factors leading to repeated attempts to reduce the numbers in receipt of out-of-work disability benefits, as will be explored in some detail in Chapter 3.

Conclusion

Disabled people's relationship with the labour market has changed over the course of the last 40 years or so, both as a result of the impact of global economic developments on the British economy and of governments' responses to these developments. As discussed above, a 'hollowing out' of the labour market has seen a reduction in the type of jobs where disabled people are more likely to have been employed, while an increase in insecure employment and in high effort/low control jobs means an increase in the type of work that disabled people find hard to sustain. The result is that it has become harder for disabled people to enter and remain in employment. At the same time, governments have been motivated to push more disabled people into employment by both their desire to increase the active reserve army of labour in order to keep down inflation, and their desire to control and preferably reduce public expenditure. As further explored in Chapter 3, this has resulted in attempts to reduce the numbers in receipt of long-term out of work disability benefits (the 'stagnant surplus').

The evidence presented in this chapter supports the contention that, while there are circumstances in which disabled people are pulled into the active reserve army of labour, there are limits to which, in the current context, they can be pulled into the labour force, even when the economy is close to technical full employment as it is at the time of writing (2017). This is illustrated by the fact that that the number of people on out-of-work disability benefits has failed to fall significantly and that, despite governments' attempts to make disabled people more 'employable', the disability employment gap has remained more or less stable, falling by only 2 per cent between 2014 and 2017.

As Macnicol identifies, and as will be further explored in Chapter 3, 'employability' has come to mean that "economically inactive citizens should be forced, by a withdrawal of benefits, to take any job, at any wage - or to perform,

long-term, those low-paid, unattractive jobs that migrant workers are prepared to do in the short-term" (Macnicol, 2013, p.5). Yet while employers could undoubtedly do more to accommodate disabled people's requirements, their incentive to do so is diminished by the ability to fill their vacancies with non-disabled workers. Although the availability of migrant workers may decline in the coming years, the nature of 'entry-level' work is increasingly such that jobs themselves are unsuited to people with long-term health problems, particularly for people with mental health conditions as many of these jobs exhibit characteristics which create and/or exacerbate mental ill health, dominated as they are by high demand/low control jobs which are poorly paid and with little job security.

The material reality facing disabled people in the current stage of capitalism means, therefore, that large numbers remain unable to take up paid employment, with some dropping out of welfare systems altogether and becoming destitute (Fitzpatrick, et al, 2016, p.25), which in effect removes them from both the work-based and needs-based distribution systems, at least officially. At the same time, the levels of public debt created by a diminishing tax base combined with greater pressures on public expenditure, and exacerbated by the aftermath of the 2008 financial crisis, are unacceptable to the neoliberal economics which has dominated governments' policies since the early 1980s. It is this combination of factors which have led to continuing attempts to reform out-of-work disability benefits. The next chapter looks at the ways in which governments have changed the nature of, and assessment of entitlement to, out-of-work disability benefits since the 1970s. Following a discussion, in Chapter 4, of the research methods used in the primary research, Chapter 5 then looks in some detail at the development and rationale of the Work Capability Assessment, an important context to the analysis in Chapters 6 and 7 of claimants' experiences of going through the assessment.

Chapter 3: Validating Devices – how out-of-work disability benefits have changed over time

Introduction

Chapter 2 made the case that, since the 1970s, changes in the labour market and in the nature of work have created barriers to disabled people entering and remaining in employment. The disability employment gap has not improved in recent years, despite the economy being close to technical full employment. At the same time, governments have been motivated - by the need to increase the active reserve army of labour and also to contain public expenditure - to drive disabled people into, or at least closer to, the labour market. As this chapter will discuss, these factors have resulted in governments' repeated attempts to tighten up eligibility criteria for out-of-work disability benefits.

Chapter 1 discussed how the administrative category of disability is used by the State to decide who is exempt from certain obligations, such as engaging in waged labour, and as such eligible for state support as a form of re-distribution of resources. In order for this category to function, it requires a 'validating device' – a "mechanism by which society obtains knowledge about individuals for the purpose of deciding whether to give social aid" (Stone, 1984, p12). The administrative category "entitles its members to particular privileges in the form of social aid and exemption from certain obligations of citizenship" (p. 4) but it must also "maintain the dominance of the primary distributive system" (p 21). In other words, a category which exempts some people from engaging in waged labour must not undermine the system which requires people to work to create and distribute resources. This chapter will look at how UK governments have approached this problem since 1970 and the different validating devices used. The chapter is therefore concerned with an analysis of policy changes and serves as important context to the documentary analysis in Chapter 5, which interrogates the development of the conceptual framework of the Work Capability Assessment.

Since the 1970s, successive governments have tried to reform state support for those unable to engage in waged labour due to impairment and/or ill health.

Although sickness benefit was first introduced in 1911, eligibility was restricted to relatively small numbers of (mainly) men, and for short periods of time, until 1971 when Invalidity Pension and Invalidity Allowance - together known as Invalidity Benefit - (IVB) was introduced which for the first time provided support for those unable to work, who had paid sufficient National Insurance contributions, but who had not acquired their impairment via industrial injury or armed service (these already qualified for Industrial Injury Benefit or a War Pension) (Burchardt, 1999, p.5). This chapter will therefore take this - the introduction of IVB in 1971 - as the starting point for analysis of the development of policy approaches to out-of-work of work disability benefits. Since then, the numbers of people claiming this type of benefit have increased dramatically. As Figure 1 below shows, most of this increase was between its introduction, when there were 430,000 claimants in 1972/3, and the mid 2000s, when it peaked at 2.7 million (if including Severe Disablement Allowance, 2.5 million without) (McInnes, 2012) and has remained stable since then. This has been presented as constituting a "crisis" by each government since the mid 1990s (Lindsay and Houston, 2013, p 1) with arguments being made that not only is this an unsustainable burden on public spending, but that long term unemployment leads to poorer health (Brown et al., 2009; Black, 2008), an increase in poverty (Kemp and Davidson, 2010), and is "a waste of human capital, as skills and labour are haemorrhaged from the productive economy" (Lindsay and Houston, 2013, p 1).

Figure 1: Numbers in receipt of out-of-work disability benefits, 1979-2016
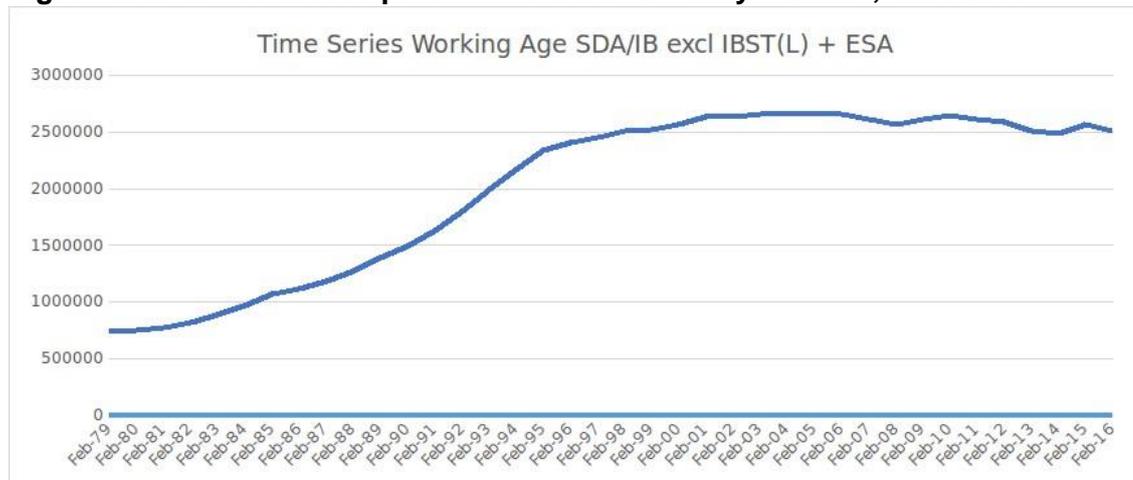
Compiled from Department for Work and Pensions, 2013a and 2017a: IBST(L) - Incapacity Benefit (Short Term Lower rate) - is excluded to make the numbers claiming different benefits with different eligibility criteria comparable over time. When compiling the data there was a difference of about 40,000 per year in the overlapping years in the two sources 2000 - 2005.

As well as looking at the various reforms different governments have introduced aimed at reducing the numbers claiming, this chapter will also identify common themes and differences in their approach towards both disabled people and to out-of-work disability benefits. It will identify how policy developments have been accompanied by changes in the validating device, reflecting changes in who is considered 'deserving' of an income replacement benefit because of illness and/or impairment, and who is treated as potentially 'undeserving' and requiring 'incentives' to fulfil their duty to be economically productive. It is this latter group who are treated as the active reserve army of labour – to be required to seek employment – while the former are part of what Marx called the 'stagnant surplus population'.

Finally, it will examine what changes have taken place in public attitudes towards welfare spending in general and disability benefits in particular, as measured by the British Attitudes survey. Attitudes towards disabled people and to expenditure on benefits are important as they can be a reflection of the messages conveyed by government as well as an indication of the extent to which government policies are either uncontentious or controversial.

3.1 The recognition of 'invalidity' as a barrier to employment

Despite the introduction of the modern welfare state during the 1940s until 1971 the only benefits specifically aimed at disabled people who were unable to work were compensation based for industrial or war injuries. As Hampton noted, what he called the "general class" of disabled people "were defined less by direct consideration of their situation and more by their comparative exclusion from the welfare state settlement", with the media and public opinion believing "there were others who more deserved support through their wartime sacrifices" (Hampton, 2016, p 53). There was widespread belief that any

support required by disabled people should be more informal and localised and not provided on a national level. Unemployment benefits were based on the insurance principle of contributing via National Insurance taken from wages. Those without enough contributions had to apply for cash payments from the National Assistance Board, but these were paid at a subsistence level in order to maintain the "incentive to attain employment" (Ibid., p 55) - the same principle of 'less eligibility' which dates back to the New Poor Law of 1834 which stipulated that conditions in workhouses had to be at such a level as to act as a deterrent to claiming relief. These payments did not take into account whether claimants were able or likely to be able to find employment and there were no additional considerations or payments if someone was disabled as there was a fear any additional payment aimed at disabled people would undermine the employment incentive and betray the contributory national insurance principle (p 57). This is also an example of role of those who are considered in the needs-based distribution system under capitalism in applying labour discipline. As already discussed, capitalism requires people to be compelled to sell their labour for it to function, as such anyone exempt from this must not be considered better off for fear it would result in others refusal to continue to sell their labour. As such those placed in this category act as a warning to those in the work-based system.

Barnes and Mercer (2004) suggest that disabled people were primarily viewed as "people in need of 'care and attention'" who were seen "as reliant on the family and friends" for any support (p.2). The one piece of policy that was directly aimed at disabled people in terms of employment was the 1944 Disabled Person's Employment Act, which saw the introduction of quotas and a focus on 'rehabilitation'. This required all employers with more than 20 employees to ensure 3 per cent were disabled. This type of approach fitted in with the general aim of full employment. However, the quota system was never well enforced and made little difference to disabled people's employment rates. Hyde has argued that the post-war employment policy deliberately excluded disabled people from mainstream employment by the provision of segregated employment schemes and sheltered workshops (Hyde, 1996). Disabled

people's place in the agenda of public policy was therefore mainly confined to social (including institutional) care issues.

During the 1960s there was increasing awareness of the links between disability and poverty, and pressure was put on the government by what was referred to as "the poverty lobby" (Whiteley and Winyard, 1984) and in particular when it came to disabled people, by the Disablement Income Group (DIG). One of the most significant and important things about DIG was that - as an organisation mainly led by disabled people and intending to be an organisation *of* rather than *for* disabled people - they focused on socio-economic issues facing disabled people rather than the charitable and medical focus of other organisations (Campbell and Oliver, 1996). This helped push the idea that those unable to engage in wage labour due to disability should be able to claim state support regardless of the origins of their impairment. DIG were instrumental in pushing disabled people from being considered as group which "could be dealt with after existing priorities" (Hampton, 2016, p 104) to one which, for example, had their own heading in the 1970 Labour party manifesto (Labour Party Central Office, 1970).

In fact, the 1970 general election saw both the Labour and Conservative Party pledge to improve the benefits for sick and disabled people (Labour Party Central Office, 1970; Conservative Party Central Office, 1970), and in 1971 Invalidity Benefit (IVB) was introduced by the then Conservative government. This was an income replacement benefit, paid at a higher rate than unemployment benefit, and intended to provide for people who were unable to work over a long period because of impairment or ill health. Eligibility for IVB was determined by "a medical assessment, by a personal doctor, of the ability to conduct 'suitable work'" (Bozio et al., 2011, p 4) meaning it could take into account a claimant's age, qualification, and likelihood of finding work (Burchardt, 1999, p 6). This accounting for the context surrounding an individual's claim and likelihood of finding work is something which, as will be discussed later, has been increasingly eroded over time.

Whereas previously only those who acquired an impairment or health condition resulting from war or industry were recognised as deserving of additional payments, now disability generally was seen as deserving of an income

replacement payment if a person's GP judged them not able to work. At this time, therefore, the validating device took the form of a person's own GP determining whether they should be exempt from seeking paid employment. An article in the British Medical Journal in 1971 sums up the shift from fearing an additional payment for those who were unable to work due to impairment or ill health would threaten the employment incentive, to a belief that those dependent on benefits for a longer period of time should receive a higher rate of payment:

> Sir Keith Joseph [the then Secretary of State for Health and Social Services] deserves credit for the efforts he has made to help the chronic sick, for it is right that they should have better benefits than those ill for short periods.

(Bayless, 1971, p 86).

At first, people were only eligible if they had paid national insurance contributions, but in 1975 Non-contributory Invalidity Pension (NCIP) was introduced for people who had not paid national insurance. This was paid at a lower rate of 60 per cent of IVB and at first was only available to men and single women. Following a political backlash to this exclusion of married or cohabiting women the government agreed to extend it to them, but only if they could "satisfy the Department of Health and Social Security that she is 'incapable of performing normal household duties'" (Lister and Loach, 1978, p 5). There was a lot of public and political objection to this at the time and eventually in 1977 eligibility was extended to married women on the same basis as men and single women (Hyman, 1982).

This Non-Contributory Invalidity Benefit was replaced by Severe Disablement Allowance in 1984 (Burchardt, 1999, p 6-7), and remained at a lower rate than the contributory ones until it was phased out for working age people in 2001. Unlike IVB and its successors, Severe Disablement Allowance (SDA) was available to people of non working age as well as working age. As this research is focused on work, any statistics presented here include only SDA claimants of working age.

Although it was a Conservative government that introduced IVB in 1971, it signalled a cross-Party approach and followed the previous Labour government's Chronically Sick and Disabled Persons Act, which had acknowledged the specific disadvantages and requirements for disabled people. However, it also fitted in with the Conservative Party "rethinking the principle of universality" and looking "more favourably on the idea of selectivity, or the concentration of aid on those in real need" (Kavanagh, 1987, p 46). The Conservative Party during the 1970s and most of the 1980s tended to treat disabled people on IVB as deserving of state aid, and to be distinguished from the 'able-bodied unemployed', a distinction made clear, for example, in the Conservative Manifesto of 1979 which insisted that "The rules about the unemployed accepting the available jobs will be reinforced and we shall act more vigorously against fraud and abuse" (Conservative Party Central Office, 1979). In contrast, the Conservative Party's first major policy statement after Margaret Thatcher was elected as Opposition Leader stated: "Our first priority must be to look after the retired, the disabled, the sick and the very poor." One of the ways they said they would do this was by keeping "the purchasing power of pensions and other long-term benefits in line with prices" (The Conservative Party, 1976).

The numbers claiming IVB rose throughout the 1970s and 1980s, to the point that they had almost tripled by 1990, increasing from 430,000 in 1972/3 to 1,265,000 by 1990/91. Most of this increase happened under the Thatcher government who yet repeatedly argued that high public spending was at the heart of the problems with the UK's economy. This, at first glance, may make the increase puzzling. However, these higher levels of expenditure were associated with the Conservative government's economic policies - as discussed in Chapter 2 - which resulted in the decline in traditional heavy manufacturing industries. Research into the demographics of those claiming IVB shows a direct correlation between high claimant areas and large scale industrial job losses (Beatty and Fothergill,1994; Lindsay et al., 2015; Webster et al., 2010)

Some commentators argued that people in these industrialised areas affected by closures and redundancies were moving onto disability related benefits,

rather than unemployment benefits, because this suited both individuals and government - individuals because IVB was paid at a higher rate than unemployment benefit and government because it kept the unemployment statistics down (McVicar, 2008, p 27). The growth in unemployment during the 1980s was certainly a political problem for the Thatcher government, and one response was the tightening of eligibility for, and a drop in the real terms value of, unemployment benefit. The government may have famously called for the rolling back of the state (Lawson, 1980), but the validating device at the time (GPs' assessments for IVB) arguably provided a useful mechanism for both controlling the official unemployment figures and helped absorb many workers that the labour market no longer accommodated. As Stone notes "in times of high unemployment, flexible disability categories provide a holding tank where otherwise unemployed people can be 'hidden'" (Stone, 1984, p 181). This is a clear example of the administrative disability category acting as a control lever on the active reserve army of labour, allowing the reserve army to contract as it absorbed workers the labour market had no use for.

The late 1970s and 1980s also saw increasing hostility and distrust of those claiming unemployment benefits, with broadsheet and tabloid newspapers alike running many stories of 'abuse' of the social security system, accompanied by accusations of 'scrounging', fraud and of people refusing to look for work and being better off on benefits than many workers (Clarke, 1983, p. 258-266). Disabled people, however, tended not to figure in these stories as the dominant public attitude was that disability meant incapacity and there was cross Party support, for example, for the introduction of Disability Living Allowance – an extra costs, non-means tested benefit - in 1992.

In the earlier part of this period, there was little done to increase disabled people's employment opportunities. The prevalent attitude that disabled people were not able to work was evident, for example, in the conclusion of the 1978 Warnock Committee that the role of education for disabled young people was to prepare them for "transition to 'significant living without work'" (Shah and Priestley, 2011, p 141). Amongst disabled people's biographical accounts of their lives during this period a desire to work was sometimes found but there were also assumptions held by disabled people and professionals with whom

they were in contact that a life on benefits was socially acceptable (see, for example, Shah and Priestley, 2011, Chapter 6). In 1981, the International Year of Disabled People, Ann Shearer wrote that by 1980 British society "was telling more and more of [disabled people] that they were excluded from this normal expectation" of employment (Shearer, 1981, p 156)

By the 1980s the quota system introduced in the 1944 Act was widely regarded as not having worked, partly because of the small number of people who could qualify to be on the disabled persons' register actually being registered, and also because of a failure to rigorously enforce any regulations against companies not meeting the quota. Only ten prosecutions were brought against employers between 1944 and 1990 (Floyd, 1991, p. 216) and in 1990 the average level of disabled people in employment within any one company was below 1 per cent (Floyd, 1991, p. 217).

Support from the government to address barriers to employment remained limited and was largely focussed on individuals, rather than on barriers created by direct and indirect discrimination (such as inaccessible workplaces and inappropriate working practices) (Berthoud et al., 1993, p. 38). The main form of support was sheltered employment:

> for those whose disabilities are such as to preclude the possibility of open employment but who are judged to be capable of achieving a productivity rate of at least 30 per cent (Floyd, 1991, p. 215).

This would seem to echo Russell's assertion that official definitions of disability are "used to classify persons deemed less exploitable or not exploitable by the owning class who control and means of production in a capitalist economy" and therefore "the prevailing rate of exploitation determines who is "disabled" and who is not" (Russell, 1984, p. 87). Most of this employment for those who were "less exploitable" was provided in workshops run by Remploy - the organisation set up under the 1944 Employment Act to run sheltered workshops and factories for disabled people - but during the 1980s the government also started to encourage sheltered, and subsidised, employment in mainstream workplaces, and by 1990 20,700 disabled people were in some form of sheltered employment of some kind (Berthoud et al, 1993, p. 47-48). About

12,000 disabled people per year also received courses of 6-8 weeks to prepare them for employment (p. 48) and in 1991, a Disability Working Allowance (DWA) was introduced as an incentive for disabled people to accept the low wages that employers were prepared to pay them.

The DWA was part of increased attention paid by the government, during the latter part of the 1980s and the early 1990s, to measures that it was hoped would encourage more disabled people into employment. There was more investment in rehabilitation and training for disabled people and the establishment of Disability Employment Advisers in local Placement, Assessment and Counselling Teams. At the same time, the government was facing pressure by a growing movement led by disabled people which, following the establishment of the British Council of Organisations of Disabled People (BCODP) in 1981, increasingly demanded legislation to outlaw discrimination in the field of employment as well as in other aspects of life (Hasler, 1993, p. 278-284). Writers and campaigners such as Michael Oliver argued that it was because of discrimination in education and employment, that disabled people were forced into "depending on welfare benefits in order to survive" (Oliver, 1993, p.271).

3.2 From 'invalidity' to 'incapacity'

Although the 1980s saw a significant increase in the numbers claiming long-term out-of-work disability benefits, it was only during the Conservative government of 1992-97 that a concerted effort started to be made to reduce the numbers claiming and, consequently, the validating device became the subject of political and public debate. During this period, the government developed four justifications for reforming out-of-work disability benefits which signalled a change in approach to long-term out-of-work disability benefits. These justifications were: the 'country' could not afford such a high level of benefits; the test of eligibility needed to be more 'objective''; the 'vulnerable' would still be 'safeguarded'; and reforms were needed to prevent fraud.

The period from when Incapacity Benefit was introduced in 1994 to replace Invalidity Benefit, to when it was replaced by Employment and Support Allowance in 2008 saw an increasing focus on whether disabled people claiming out-of-work benefits were really unable to engage in paid employment.

This focus was part of the redefining of who was 'deserving' and who was 'undeserving', raising the question - as identified in Chapter 2 - as to whether, or which groups of, disabled people should be placed in the active reserve army of labour and which should be treated as part of the 'stagnant surplus population'. There was a repeated mantra in government policy documents that "most disabled people want to work" (e.g. Prime Minister's Strategy Unit, 2005), a claim also often made by the disability rights movement which sought to reframe disability as a civil rights issue (Campbell and Oliver, 1996). However, in the case of the Conservative and then Labour governments, this stance went alongside increasing questioning of whether many claimants were in fact too sick or disabled to work. This also led to repeated attention being paid to the effectiveness of the validating device, the mechanism for assessing entitlement to benefits, and whether it was effective at separating out those who should be placed in the active reserve army of labour from those who were considered to be exempt from the obligation to seek employment (the 'stagnant surplus population')

By 1994 the cost of out-of-work disability benefits had quadrupled since 1978/9 (Strickland, 1994, p. 3) as the numbers claiming had risen from 430,000 in 1972, to almost 1.5 million by 1993 (p. 2). The then Conservative Prime Minister John Major stated that it "beggars belief that so many more people have suddenly become invalids" (Major, 1993, col 732) and Peter Lilley, the then Secretory of State for Social Security, stated that "the rules have been progressively widened and complicated" and the definition of incapacity had become "fuzzy" (Lilley, 1994, col 35). The government therefore proposed replacing IVB with Incapacity Benefit (IB) and introducing a new test called the All Work Test, to assess claimants.

When Peter Lilley introduced the Social Security (Incapacity for Work) Bill into the House of Commons in 1994 he illustrated the four themes mentioned above. "Spending on invalidity benefit has doubled in real terms in the past 10 years, from £2.7 billion to £6.1 billion last year" he said. "If we left it unchanged, it would grow by a further 50 per cent. or more in real terms by the end of the decade" (Lilley, 1994, col. 35). In response, the government would introduce a

"new and more objective test" which would determine eligibility for a new benefit - Incapacity Benefit - which would replace Invalidity Benefit.

In introducing this new benefit, Peter Lilley said, the government was aiming to "safeguard the position of the most vulnerable" and "to ensure that the huge and rising sums devoted to sickness benefits are properly focused on those who are genuinely too unwell to work". The Bill, he said, "is not an attack on the sick and disabled; it is the very reverse. It is designed to protect their benefit against those who abuse it" (Ibid).

The government was therefore putting forward four justifications for the new benefit: the rising cost of the old benefit was not sustainable; a new benefit would have a 'more objective' test of eligibility; this would 'safeguard the most vulnerable'; and prevent fraud (with the implication that the current test and benefit encourages fraud). These last three themes were all concerned with who is 'really disabled' and also underpin the changes to the administrative categorisation of disability and the accompanying validating device which have taken place since then.

The political rhetoric, as illustrated by the above quotes from Major and Lilley, was focused on disbelief that so many people could possibly be too sick/disabled to work, and the government was accused of trying to paint disabled claimants as "lead-swingers and idlers" by the Disablement Income Group (Strickland, 1994, p. 23). Although Government Ministers claimed that it had become easier to claim IVB over the years, government-commissioned research concluded that "There is virtually no direct evidence that the threshold between being judged 'fit for work' and 'incapable' has changed over the years. There is, however, some evidence that the chances of employment have declined for people on the borderline" (Ibid., p. 5). A summary of the issues prepared by the House of Commons Library acknowledged that there are people who "may be capable of work in the most literal interpretation of the phrase" but that, due to both lack of labour market demand and employers' prejudice and or expectations, their "disability prevents them from working" and asked the question whether these people should receive disability benefits or be just considered "unemployed, expected to live on the lower-level short-term benefits, and asked to demonstrate that they are actively seeking work?" (Ibid,

p. 5). While there was no evidence that it had become easier to claim long-term out-of-work disability benefits, what had changed was the government's approach to this group of people who were supported through the 'needs-based' rather than the 'work-based' distribution system. Previously, as described in Chapter 2, the government had pursued policies which facilitated the development of a flexible labour market in the context of globalisation, and had - as described above - tolerated an increasing number of people on long-term out-of-work disability benefits. Now, as also discussed in Chapter 2, they turned their attention to trying to pull these people into the active reserve army of labour, partly motivated by the desire to bring down public expenditure and partly by concerns about wage inflation as the economy picked up and unemployment fell.

The first stage in the attempts to shift people from the 'stagnant surplus population' to the active reserve army of labour was to change the validating device by eliminating the eligibility criteria which linked the claimant's previous occupation, qualifications and experience to receipt of long term benefits. Despite research acknowledging that the labour market was a crucial factor in the increase in IVB claimants the government introduced a test which had a focus on "whether there is any work the claimant could perform, regardless of the likelihood of him or her getting such a job or its suitability" (Burchardt, 1999, p. 6). Eligibility for IVB had been determined by an applicant's GP's assessment as to whether they were able to do their usual occupation. In contrast, the All Work Test for IB set out to assess whether an applicant could do a range of activities. These "descriptors" were grouped in two parts, "physical disabilities" and "mental disabilities" and included, for example how far someone was able to walk, whether they could sit "comfortably" in a chair, bending and kneeling, lifting and carrying, concentration, interaction with others, and so on (Department for Social Security, 1995, no pagination).

This marked a fundamental shift in how eligibility to an income replacement benefit on the grounds of disability was determined. Whereas previously, IVB entitlement was on the basis of the opinion of a person's GP as to whether they were fit to return to their usual occupation or similar - an assessment which was, arguably, fairly closely related to the likelihood of the individual being able

to return to work - now, entitlement was to be determined by a doctor appointed by the Department for Social Security and assessment was about basic functional incapacity. This type of assessment has been described as a "functional capacity assessment" which "relies upon assessing the level of ability for a number of different activities, which together yield a form of 'ability profile' for the individual" (Council of Europe, 2002, p.18). As we shall see, each subsequent reform of the validating device has also followed this approach, where "the focus is upon the ability of the individual to labour, rather than upon the ability of labour market institutions to facilitate the employment of her or him" (Grover and Piggott, 2007, p. 739).

The new assessment was immediately met with concern from organisations representing disabled people. The Disablement Income Group argued that it "fails to take account of the reality of there ever being the kind of employment opportunities for which a person with those disabilities is suited" (Strickland, 1994, p.24); the Disability Alliance stated that "Non-medical factors are relevant and should be taken into account. Other factors which interact with disability have an impact on work capacity." (p. 25); and the Disability Benefits Consortium concluded "isolating the ability to perform work-related tasks cannot take into account the realities of actual workplaces and the demands of employers for a flexible and reliable workforce" (p. 28). These are very similar to the arguments being made about the Work Capability Assessment and reflect the fact that although the WCA was cited as 'more objective' than its predecessors, it in fact has many similarities.

Despite the intention that the All Work Test would reduce the numbers receiving IB, the reforms introduced in 1994 failed to make a difference to the claimant levels, as can be seen from Figure 1 above. When Labour came into office in 1997, there was renewed attention paid to the need to prevent wage inflation as unemployment came down. New programmes to expand the active reserve army of labour were introduced, initially aimed at lone parents and the long-term unemployed but soon extended to people in receipt of out-of-work disability benefits, as discussed in chapter two.

Frank Field MP was tasked with developing "a political and intellectual framework" for reform of the welfare state and the direction of travel was given

by Prime Minister Tony Blair who stated in his Foreword to the resulting green paper: "We want to rebuild the system around work and security. Work for those who can; security for those who cannot" (Department for Social Security, 1998, p.iii). The consultation paper asserted that the current system contained disincentives to work and that fraud was taking money out of the system and away from 'genuine claimants'. It proposed a 'third way' approach to the welfare state - neither a residual safety net nor a system of generous benefits which created 'dependency' but instead offered 'tailor-made' help to enable people to escape from the "cycle of dependency" (Hollis, 1998, Col. 1364). Increasingly, the charge of 'welfare dependency' which the previous Conservative governments had primarily levelled at the unemployed was now also applied to people on long-term disability benefits.

This shift was clearly linked to a desire to reduce social security spending, as illustrated by a leaked document in 1997 which stated that "it is likely that a high proportion of the necessary savings will have to come from benefits paid to sick and disabled people" (quoted by Piggott and Grover, 2009, p.161). This was confirmed the following year when the Labour government published *New Ambitions for our Country: A new contract for welfare*, which proposed to "reduce spending on Incapacity Benefit" by "fundamentally" reforming the benefit (Department of Social Security 1998, p. 12). Changes were made to the assessment and eligibility criteria for Incapacity Benefit which purported to reflect a shift away from seeing disabled people as 'dependent' and in need of 'care'. The All Work Test was replaced by a new validating device, the Personal Capability Assessment, and "Much was made in the run up to the publication of the proposals of the idea that a new test for Incapacity Benefit would focus on what claimants could do rather than what they could not" (Burchardt, 1999, p.12) with government guidance stating, "It focuses on what people can do despite their illness or disability as well as determining if the incapacity threshold is met" (Department for Work and Pensions, n.d). However, the descriptors remained essentially the same as the All Work Test, in that they were intended to 'objectively' measure functional limitations.

The Personal Capability Assessment, again like the All Work Test, did not attempt to assess whether a person was actually likely to gain employment, as

illustrated during the course of the Welfare Reform and Pensions Bill's passage through Parliament, when the government's spokesperson in the House of Lords made clear that the "benefit does not hinge on anything to do with the employment situation" and the assessment "is not related to employment prospects" (Hollis, 1999, col 292). This remains the case with the WCA and was repeatedly brought up by research participants as a concern, as shown in Chapter 6.

This was a period of declining rates of unemployment and increasing employment opportunities in the service sector, factors which it might have been assumed would - combined with tighter eligibility criteria for out-of-work benefits and employment support programmes for disabled people such as the New Deal and Pathways to Work - reduce the numbers claiming Incapacity Benefit. One of the rationales for the Personal Capability Assessment was that, although it did not change the threshold at which someone became eligible for IB, it aimed, as a Government Minister explained, "to provide additional constructive information about what a person can do, despite their medical condition or disability" with the intention that "this additional information will help personal advisers give their clients the support they need to move back to work" (Bayley, 1999).

It was also a period during which the government renamed the Department for Social Security as the Department for Work and Pensions, a change in name which it could be argued signalled the gathering pace of the shift (started under previous Conservative governments) from a Keynesian welfare state to what has been called a 'workfarist' state. As Grover explains, this term describes the situation where:

> social policy has become central to economic restructuring aimed at supporting 'free' markets, rather than being concerned with protecting universal rights that were associated with Keynesianism.

(Grover, 2003, p.18)

At the same time, a focus on helping people into work and implementing the Disability Discrimination Act (passed by the Conservative government in 1995 but with more emphasis put by Labour on implementation) chimed with

disabled people's campaigns for equal citizenship and a 'right to work'. However, the Labour Government's encouragement of 'active citizenship' - with their emphasis that 'rights' went with 'responsibilities' - was a key part of the attack on 'dependency' on benefits. Prime Minister Tony Blair, in a speech on welfare reform in 2002, set out a vision of "A welfare state based on rights and responsibility where we gave opportunity to people on benefit to get into work; but demanded responsibility in return" and Home Secretary David Blunkett said, "a citizen cannot truly be an equal member of the community if he or she is reduced to a state of permanent dependency on the support of others" (Blunkett, 2003, p. 16).

By the early 2000s it was becoming clear that neither the introduction of the Personal Capability Assessment nor 'welfare into work' programmes such as the New Deal and Pathways to Work were making a significant impact on the numbers claiming IB, which reached 2.7 million by 2002. In response, the Department for Work and Pensions commissioned Gordon Waddell and Mansell Aylward (who was the DWP's Chief Medical Officer) "to develop a theoretical and conceptual framework for incapacity benefits for people of a working age" and "to provide a scientific evidence-base for IB reform to meet today's challenges and needs" (Waddell and Aylward, 2005, p. 7). The development of this framework and its application to out-of-work disability benefits is analysed in some detail in Chapter 5 but its implementation in the context of welfare reform is discussed in the next section of this chapter.

3.3 From Incapacity Benefit to Employment and Support Allowance: reducing the 'really disabled'

The four themes discussed above which underpinned the Conservative government's approach to out-of-work disability benefits since the early 1990s - the aim of cutting the money spent on such benefits, applying an 'objective' test of eligibility, 'safeguarding the most vulnerable' and preventing fraud - were all apparent during the Labour government of 1997 to 2010, together with, as mentioned above, an increasing focus on 'welfare dependency' amongst those on out-of-work disability benefits. As Chapter 2 identified, there was also a focus on work being the best route out of poverty (Department for Social

Security, 1998, p. 1) and that work is good for people's health (see, for example, Waddell and Aylward, 2005, pp.17-22). These two contentions were a key part of the Labour government's case for replacing IB with Employment and Support Allowance in 2008, and remained an argument put forward by both the Coalition government of 2010-2015 and Conservative governments. The message "of work as the 'best form of welfare' and the only economically and morally sustainable route out of poverty" (Grover and Piggott, 2007, p.743) has, as we shall see, been a consistent refrain.

In 2006, the Labour government published a Green Paper, *A New Deal for Welfare: Empowering People to Work* (Department for Work and Pensions, 2006). This proposed to reform IB, stating that "everyone should have the right to work and the right to support and help to enable them to do so" (Ibid.,p. 9). The dominant thread throughout this Green Paper was one of 'Rights and Responsibilities' and "the principle that the best welfare policy of all is work" (p. iv). The argument that people have a responsibility to move into work "when they have a level of capacity and capability that makes this possible" (p. 2) went along with the need to limit public expenditure - a need created by the type of economy Britain now faced and evident even before the financial crisis of 2008 (as discussed in Chapter 2) and by the dominant All Party support for low taxes.

In order to deliver the aim of eighty per cent employment (set out in the 2006 Green Paper), an aim which reflected a desire to both increase the active reserve army of labour and cut social security expenditure, the government proposed that 1 million people would need to be got off IB and into work. The numbers claiming IB had in fact started to fall by 2006 but this was almost entirely due to larger percentages of those coming onto the benefit leaving it within 6 months to a year. In his 2007 report, David Freud, appointed as a special advisor to Tony Blair, pointed out that 2.3million (85 per cent of the total) had been on IB for over a year and that the two groups who were now more common amongst new claimants were "a new generation with manageable mental health or musculoskeletal conditions" (Freud, 2007, p. 27) - a contention which, as Chapter 5 will establish, was at the heart of the new

'theoretical and conceptual framework' for assessing incapacity to work which was set out in Waddell and Aylward's 2005 report. Freud argued that:

> A system based on a presumption of robust self-reliance will require an entirely different set of rules than one in which significant parts of society are not given the opportunity of, or expected to, work. The difficult heritage of the passive labour market policies of the 1970s is one of welfare dependence rather than self-reliance. One of the objectives of this reform must therefore be to generate clear signals around independence, respect and mutual obligations.

(Freud, 2007, p.46)

Increasingly, the claim that 'the unemployed' were not meeting their social obligation to seek work was now applied to disabled people, with the assumption that at least some and possibly many must be undeserving of the state support they were receiving. The rhetoric surrounding policy approaches to disability benefits, by both Labour and the succeeding Coalition government, was of how the level of claims represented a crisis, in that they were too generous – both in their monetary value and ease to claim - and that a 'dependency culture' had emerged with individuals needing to take more economic responsibility with increasing obligations to move off benefits (Department for Work and Pensions, 2008b; Freud, 2007). This was twinned with the idea of "too many sick and disabled people languishing in a life without work" (Duncan-Smith, 2015) and that this needed be addressed by increasing obligations from recipients and making sure "work always paid" (Ibid). As in the earlier stages of the post-Second World War welfare system, this means that the Poor Law principle of 'less eligibility' - seeking to ensure that those receiving out-of-work benefits are always worse off than those in work - remains an important aim and reflect the importance to capitalism of compelling people to sell their labour as discussed in chapter 1. Although policy debates were, and continue to be, also accompanied by insistence that there would always be support for the 'most vulnerable', the implication of 'making work pay' is that benefits should always be less than what someone would receive in waged employment. The result is that relying on out-of-work benefits creates a high risk of living in poverty, as for example illustrated by the Joseph Rowntree

Foundation's work on a Minimum Income Standard illustrates (e.g. Padley and Hirsch, 2017), and living in poverty only increases 'vulnerability' to all the disadvantages associated with a low standard of living.

The introduction of ESA in 2008 saw out-of-work disability benefit claimants split into two groups. One is the Support Group, who are those considered as a result of the 'severity' of their impairments not to be capable of or expected to engage in paid employment in the longer term. This is paid at a higher rate, but is subject to more frequent reassessment than any of its predecessors. The other group is the Work Related Activity Group (WRAG), consisting of those who are deemed able to work in the future, and capable of working towards this, but who need support to do so. This group continue receiving impairment/illness related income replacement benefits, but they are set at a lower level than for those in the Support Group (but until April 2017 higher than Job Seekers Allowance). Recipients are regularly reassessed and have increasingly faced a number of conditions and potential sanctions for non-compliance.

As Bambra and Smith identified, Labour's introduction of Employment and Support Allowance signalled the beginning of a new phase of approaches to out-of-work disability benefits, and to disabled people, "one that could be considered as a move towards making these recipients subject to 'workfare'" (Bambra and Smith, 2010. p. 74). By insisting that it was legitimate to compel disabled people to carry out certain requirements in return for receipt of benefits, Labour was applying its 'rights and responsibilities' agenda to people placed in the ESA Work Related Activity Group. The division between the Support Group, who were deemed unable to either work or engage in work-related activity, and the WRAG signified that the latter would only 'deserve' their benefit if they participated in activities intended to get them 'back to work'. The spitting of long-term out of work disability benefits into these two groups can also be seen as a concerted attempt to dramatically reduce the size of the 'stagnant surplus population' and in doing so to move significant numbers closer to the active reserve army of labour. Indeed, as discussed later in this Chapter, the more recent changes to the WRAG are arguably moving it onto a more or less equal standing with Job Seekers Allowance (JSA) and it may

represent the start of a shift to make the WRAG obsolete, and again widening the active reserve army.

When the Coalition government took office in 2010, it committed to the full implementation of ESA, including the reassessment of those on IB. In addition, it limited contribution-based ESA for the Work Related Activity Group to one year, on the grounds that, as the now Conservative Minister, Lord Freud argued:

> this supports the intention that ESA should be a temporary benefit for the vast majority of people - which indeed it is. This is particularly true of those in the work-related activity group, who are assessed as likely to recover and make an eventual return to work.

(Freud, 2011, col.631).

Further reforms in 2012 saw this group broken down further, based on the expected length of time each claimant is considered to be away from returning/entering the labour market, with those groups considered closer to it having more conditionality placed on them (Patrick, 2012; Department for Work and Pensions, 2012). These conditions are focused on the supply side of labour and designed to increase an individual's 'employability', and include requirements to, for example, attend Work Focused Interviews, undertake skills training, draw up a CV, carry out 'work experience' and community work placements. With the exception of 'work experience', a failure to comply with these conditions can result in a withdrawal of benefits for up to a month. Mandatory Work Experience was introduced in 2011 but the programme was not renewed in 2015 after significant controversy about its legality and efficacy.

Whereas previously those claiming out-of-work disability benefits were not subjected to conditionality (bar the assessments to qualify) in order to continue receiving their benefits, since 2010 those in the WRAG have had increasing conditionality placed on them. The increasing use of sanctions - withdrawal of benefits for set periods of time - was motivated by the popularity amongst government and civil servants of behavioural theory which contended that the greatest incentive to action was to avoid loss (see, for example, Cabinet Office

and Institute for Government, n.d.), an assumption crucial to neoliberal economics' assumption of individuals as 'rational actors'.

By March 2016 the Work Programme had implemented 175,000 sanctions for those in the WRAG, whilst at the same time only moving 36,986 into work (Webster, 2016). This seems to demonstrate the limits of a supply side focus and intervention in moving people into work, and also means 175,000 disabled people found themselves without payments for a period of time. Conditions and sanctions rest on the assumption of the 'rational actor', a person acting rationally in their financial best interest, but there is increasing evidence that sanctions do not increase the likelihood of employment (Loopstra et al, 2015). Instead they only create financial crises for already poor households, increase the use of food banks and the risk of becoming 'disconnected' from the welfare system altogether (Loopstra et al, 2016, Baumberg Geiger, 2017a). While the level of sanctions has declined from its peak in 2013, 44,300 people in the Work Related Activity Group had their benefit reduced or withdrawn for a period during the year to June 2017, the great majority for a failure to engage in work-related activity (Department for Work and Pensions, 2017a, p.6).

The assumption that people on out-of-work disability benefits will be 'incentivised' by financial loss to enter employment remained at the heart of the government's approach and, in April 2017, the rate of benefit that those in the WRAG receive was cut by nearly £30 for new claimants, to make the benefit the same amount as that for Job Seekers Allowance (Department for Work and Pensions, 2017b). The government argued that people were more likely to move from JSA into employment than if they were in the Work Related Activity Group and therefore this reduction in benefit levels would "remove the financial incentives that could otherwise discourage claimants from taking steps back to work" (Department of Work and Pensions, 2015, p 1). As Grover (2015) has argued, this is an example of the government failing to understand that those in the WRAG are there due to health conditions/impairments which will make moving into work a lot less likely than someone on JSA. It demonstrates how much the administrative category of disability has been tightened, to the extent that those in the WRAG are increasingly viewed as the same as those unemployed and as such part of the active reserve army. The government

aimed to soften this cut by declaring that alongside addressing the 'financial incentive' to people remaining on ESA they would be using the savings made by the cut in benefits paid to provide more funding for individual support to get people into work. However, it is worth noting that the amount the government has committed towards increasing this funding equals less than one sixth of the saving made by the cut to the WRAG (Grover, 2015, p 1576). At the same time the 52 week limit on 'permitted work' alongside benefits was removed, as long as claimants work fewer than 16 hours per week and earn less than £120 per week. This change was also explicitly premised on the policy belief that "Work is generally good for physical and mental wellbeing" and that it may help claimants to "learn new skills, build their confidence, start thinking about types of work they could do when they are able" (Department for Work and Pensions/Department of Health, 2017).

As discussed in Chapter 2, there is very little evidence that these types of supply side interventions will have any real success at actually moving people into work, though they may be removed from benefits altogether as a result of sanctions (as discussed above). As we shall see, in Chapter 5, the assessment of eligibility for ESA does not seek to measure the likelihood of someone being able to get employment. Instead the assessment is narrowly focused on functional abilities. Research into the employment outcomes of those who had been through the WCA found that just nine per cent of those in the WRAG had moved into work. Those who had been assessed but found Fit For Work fared better, experiencing a twenty-five per cent return to work rate, but this is arguably still very low (Sissions and Barnes, 2013). There have been suggestions that demand side policies have also had little impact, with financial incentives to employers to hire disabled people failing "because they did not adequately offset the perceived risks and costs of employing a disabled person" (Grover and Piggott, 2015, p. 202) and legislation having had little impact due to employers not being aware of it (Roberts et al., 2004). However, both of these suggest more a problem of implementation than proof that such interventions will not work. There is evidence that when people were able to use interventions such as Access to Work, which addressed workplace accessibility, this has a positive impact on employment rates (Grover and

Piggott, 2015, p. 215) although the potential of such support is now being diminished by a cap being put on the amount of money available to each applicant, as announced in the recent White Paper *Improving Lives: The future of work, health and disability* (Department for Work and Pensions/Department of Health, 2017). It signifies yet another step in attempts to move more and more disabled people into the position where they are required to make themselves available to be drawn into the labour force (i.e. into the active reserve army).

Since its introduction in 2008, and particularly since the full roll-out from 2010, the WCA has come under increasing criticism. A detailed consideration of the theoretical framework which informs this validating device is the subject of Chapter 5, and Chapter 7 uses primary research of the experience of undergoing a Work Capability Assessment in order to understand the nature of the relationship which is being played out in the assessment process. This current chapter confines itself to a brief outline of the implementation of the WCA and the further developments announced in 2017.

When it introduced ESA and the WCA, the Labour government had expected "around 90 per cent of claimants to be placed in the Work Related Activity Group" (Department for Work and Pensions, 2008b, p.86) and intended that half of new claimants would be found fit for work and not eligible for ESA (Department for Work and Pensions 2007b). The numbers placed in the Support Group were therefore expected to be very much in the minority and such an outcome would of course have dramatically reduced the 'stagnant surplus' population, making many more disabled people available to be moved into the labour force. However, as discussed below, this did not turn out to be the case. Nor was the goal achieved of half of new claimants being found fit for work. In the first few years of the WCA, thirty-two per cent of new claimants were found fit for work (House of Commons Work and Pensions Committee, 2011, para. 153) and there was a thirty-six per cent appeal rate, of whom thirty-nine per cent were successful. Following the first official independent review into the WCA it was concluded that the assessment in "its original form did not properly assess some types of conditions, including those relating to mental rather than physical issues, and those that are non-continuous" (Webster et al.,

2013, p. 188). This was followed by a high court ruling in 2013 that found that the WCA "disadvantages people with mental health problems, learning disabilities, and autism" (Rethink, 2013).

Another criticism of the WCA was that it does not allow for the combined impact of multiple health conditions/impairments to be considered when assessing someone's 'fitness' for work. Two thirds of ESA claimants have reported having multiple conditions (Barnes and Sissons, 2013, p. 77) but, whereas the Personal Capability Assessment criteria enabled recognition of the combined impact, the WCA does not. This, claim Barnes and Sissons, has led to Job Centre Plus staff reporting that people who have been sent to see them due to being in the WRAG as being more unwell than any IB claimants they had previously dealt with (p. 87).

Since the introduction of the WCA and particularly since its full implementation under the Coalition government, there had been growing protests by disabled people against the company contracted to carry out the assessment, Atos, and in 2014 they withdrew from their contract early. A Work and Pensions Committee report into the WCA in 2014 declared it "not fit for purpose" and called for a "fundamental redesign" (House of Commons Work and Pensions Committee, 2014). However, the Conservative government continued to defend the system until suggesting in a 2016 Green Paper (Department for Work and Pensions/Department of Health, 2016) that they would consult on making changes to the WCA. Nevertheless, at the time of writing (December 2017) no changes have been made to the assessment itself. Instead a new stage of the process has been introduced, as well as a reissuing of guidance around an important regulation as discussed below.

3.4 Recent developments in the validating device

By the time the Conservative government was elected in 2015, a consensus was emerging amongst Ministers that the WCA was not delivering, and was unlikely to deliver, the reductions in the numbers deemed eligible for out-of-work disability benefits. It was also becoming clear that - far from ESA being a "temporary benefit for the vast majority of people" (Freud, 2011, Col. 628) - the largest group was those in the Support Group who, by May 2017 made up 66 per cent of the total of ESA recipients (Department for Work and Pensions,

2017c). Numbering 1.5 million people, they accounted for 74 per cent of total spending on incapacity benefits (Emmerson et al, 2017, p 180) and meant that there were 50 per cent more people in the Support Group than the combined numbers in the Work Related Activity Group and on JSA (p.196), a point not lost on the government who, as we shall see, have started to pay more attention to bring those in this group closer to the labour market.

At the same time, the Behavioural Insights Unit - whose previous work had heavily influenced the introduction of conditionality and sanctions - concluded that sanctions were not actually achieving the intended outcome of increasing entry into employment (Gandy et al, 2016). This then throws into question the validity of the 'rational actor' approach to benefits, whereby both the level of benefits and the conditions attached to them are seen as acting as incentives to 'getting off benefits'.

Soon after the 2015 general election Iain Duncan Smith, Secretary of State for Work and Pensions between 2010 and 2016, announced that the government was going to reform the system of assessment for out-of-work disability benefits yet again. He reiterated the goal first set by Labour in the mid-2000s of getting one million people 'off benefits', arguing - as Labour did when replacing the All Work Test with the Personal Capability Test in 1998 - that the assessment needed to be about what people could do rather than about what they could not (Duncan Smith, 2015).

Lord Freud, then Minister for Welfare Reform, told the annual IntoWork conference in July 2016 that the Work Programme had been designed for a time when unemployment was high. In contrast, "The labour market we have now" he told them, "is one with a record employment rate. What remains is not cyclical unemployment but structural unemployment" (Freud, 2016, no pagination). Both he and the Secretary of State were signalling that the problem was now people "whose conditions are stopping them from finding and staying in work" and, he said, the government would aim to help them "overcome" and "manage" these health conditions (ibid).

The WCA, as a validating device, had been intended to reduce significantly the proportion of those eligible for out-of-work disability benefits whose

impairments and/or health condition were recognised as absolving them from making attempts to move closer to the labour market. While this was initially achieved in that the majority of those deemed eligible for ESA were placed in the Work Related Activity Group, the situation is now reversed and, as discussed above, far higher numbers are now placed in the Support Group.

Initially, the government tried to tackle this by reissuing guidance on a particular regulation which seemed to have brought about an unintended increase in the numbers placed in the Support Group. The fifth and final independent review into the WCA noted that the majority of this increase appeared to be down to people being put in the Support Group under this regulation. What is particularly important and interesting about this regulation is that it operates outside of the points based system that the rest of the assessment is done on. It forms part of two regulations of which the first (regulation 29(2 b)) allows people who may not have received enough points via the functional assessment to be found to have Limited Capacity for Work – and as such be placed in the WRAG – and the second (regulation 35(2 b)) then applies if those people are found to have Limited Capacity for Work Related Activity and they are put into the Support Group. These regulations apply "where there is deemed to be a substantial risk to the mental or physical health of any person" (Centre for Health and Disability Assessments, 2018, p 138) if the claimant is expected to either work or engage in work related activity.

In the fifth and final independent review of the WCA in November 2014 Litchfield (2014) said:

> "it seems clear that the original belief was that this would constitute the least likely outcome of the WCA and that Regulation 35 would only be used in exceptional circumstances" (p 34)

Despite this his review had found that the increase in Support Group outcomes between 2009 and 2013 was largely due to the increase in the use of regulation 35(2 b). There was an increase from 17% to 38% between 2009 and 2013 (p 36). This is perhaps an example of the limitations of a functional points based assessment as a tool to truly capture the impact of work or work related activity and as such someone's ability to engage in them. However, Litchfield

recommended that the use of this regulation warranted "close scrutiny" (p 41). Following the 2015 general election the Conservative government reissued the guidance around both regulation 29 and regulation 35. This was followed by a significant reduction in the numbers both in the Support Group as a whole and those qualifying via regulation 35 in particular. Prior to this reissuing of the guidance the percentage of Support Group outcomes for initial assessments due to "mental or physical risk" peaked at 53% in February 2015. By June 2017 it had more than halved to 24% (Department of Work and Pensions, 2018, Table 5). This change in guidance and fall in the use of regulation 35 for those being put in the Support Group, and in the overall Support Group numbers, ultimately means that many people who previously would have found themselves in the Support Group are now being pushed either into the active reserve army, by being found Fit For Work, or at least a lot closer to it, by being put in the WRAG.

At the same time as tackling the unintended impact of regulation 35, the government made a series of announcements which were aimed at moving yet more disabled people into the active reserve army of Labour. For instance, Lord Freud, then Minister for Welfare Reform, told the annual IntoWork conference in July 2016 that the Work Programme had been designed for a time when unemployment was high. In contrast, "The labour market we have now" he told them, "is one with a record employment rate. What remains is not cyclical unemployment but structural unemployment" (Freud, 2016, no pagination). Both he and the Secretary of State were signalling that the problem was now people "whose conditions are stopping them from finding and staying in work" and, he said, the government would aim to help them "overcome" and "manage" these health conditions (ibid).

In effect, the government now embarked on yet another attempt to reduce the 'stagnant surplus' population, those considered to be 'deserving' of support (the ESA Support Group). Thus, the Secretary of State announced in 2016 that the government recognised that a minority of those in the Support Group, "who have severe, lifelong, often progressive and incurable conditions, with minimally fluctuating care needs" were "unlikely to ever be able to move closer

to the labour market and into work" (Green, 2016). Therefore, they would not be required to be reassessed by the WCA.

This announcement was followed later in the year by a Green Paper, *Work, Health and Disability: Improving Lives* (Department of Work and Pensions/Department of Health, 2016) which signalled the government's intention that the majority of people in the Support Group would now be required to engage with Job Centre Plus in the same way that those in the Work Related Activity Group have been required to do. The Green Paper proposed a Health and Work Conversation as the mechanism for doing this, and for fulfilling David Freud's previous announcement that the government should help people to "overcome" and "manage" their conditions so that they could get into work (see above). This would be a key part of the process of applying for and maintaining eligibility for ESA and would be a requirement while new claimants are waiting for their Work Capability Assessment and also for both those in the Support Group as well as those in the Work Related Activity Group who are being reassessed, although the compulsory element of any action required following the 'conversation' will (for the moment at least) only apply to those in the Work Related Activity Group. As Grover (2017) has pointed out:

> In the future, when there is even more individualised (described as 'personalised' in *Improving Lives*) employment support, based upon the discretion of work coaches, the potential is for conditionality to be extended to *all* ESA claimants, with perhaps (although because it will be discretionary this cannot be guaranteed) the exception of the category of people with the 'most severe lifelong conditions'. (p, 1272)

In November 2017 a White Paper - *Improving Lives: the future of work, health and disability* (Department for Work and Pensions/Department of Health, 2017) - was published which followed the Green Paper and this is discussed in more detail in the concluding chapter with an examination the most recent policy developments concerning the validating device. In summary, recent developments are just the latest stage in the state's attempts to 're-make' the working-age disabled population, as discussed in the previous chapter. The

validating device, the mechanism used to determine who should be exempt from the obligation to sell their labour, has been revised in ways which reflect ideas about, not just what 'fit for work' means, but also the nature of barriers to work and how they should be overcome. The theoretical and conceptual framework behind the current validating device, the Work Capability Assessment, is explored in some detail in Chapter 5, in an attempt to understand how disabled people's lived experiences have come to be treated as contentious and replaced by the state's definitions of what it is to be disabled.

The changes in policies which have resulted in a redefining of who is 'really disabled' also influence, and are reflected in, changes in public attitudes towards disabled people. The final section of this chapter looks briefly at how attitudes have evolved, with particular reference to the British Attitudes Survey.

3.5 How did public attitudes towards disability benefits change?

Started in 1983 the British Social Attitudes Survey aims to capture the general British public's feelings towards different matters. One area surveyed is attitudes towards welfare and government spending. On the face of it attitudes towards government spending on disability benefits have not changed much at all, with 58 per cent thinking that the government should spend more on disability benefits in 1983 and 61 per cent in 2015 (National Centre for Social Research, 2016a). However there have been fluctuations within this time. For example, between 1989 and 1994 there was a 9 per cent drop from 60 to 51 per cent thinking the government should spend more on disability benefits. This coincides with the change from Invalidity Benefit to Incapacity Benefit and may have had some influence on the government's spending priorities or it may indicate that government rhetoric about needing to cut spending and numbers on disability benefits influenced public opinion (see below). This rose again to 61 per cent by 2000, only to fall back to 53 per cent in 2010, although it rose back to 59 per cent by 2012. However, this question is presented as a broad definition of 'disability benefits' and as such may not accurately represent attitudes to out-of-work disability benefits.

When a question is asked about attitudes towards spending on disability benefits for 'disabled people who cannot work' there was a significant drop in support for spending between 1998 (the first year this was measured) and 2011, of 72 to 53 per cent (National Centre for Social Research, 2016b). This rose again to 61 per cent by 2015, suggesting at least a small backlash to the Coalition government's approach and the increasing publicity about how policy was having a detrimental impact on people's lives. There has been consistently high support for increased government spending on "people who care for those who are sick or disabled", which perhaps says something about how disabled people are viewed still as objects of care rather than independent individuals. However even this support saw a 10 per cent drop between 2008 and 2013 from 83 to 73 per cent.

When looking at attitudes towards unemployment benefits generally there is a long term trend towards both less support as a spending priority and an increase in the belief that they are too high and create a disincentive to work. Between 1988 and 2008 there was over a 20 per cent increase in those who said employment benefit was "too high and discouraged work". The same time period saw a 30 per cent decrease in those who thought it was "too low and caused hardship". The numbers who agreed that "large numbers of people these days falsely claim benefits" also saw a shift during the same time period with a 17 per cent increase (National Centre for Social Research, 2013).

Support for unemployment benefits being a government spending priority fluctuated from 35 per cent in 1984 to 21 per cent in 1990, then it briefly rose to 26 per cent in 1996 before dropping to 13 per cent by 2000 and was only 7 per cent by 2007. This drop coincides with an economic boom and growth in jobs, which may make people more likely to think that less should be spend on unemployment. Since the economic crash this has seen a slight increase to 13 per cent by 2014 (National Centre for Social Research, 2015). The numbers who agreed that "around here, most unemployed people could find a job if they really wanted one" also seems to fluctuate in line with the general strength of the economy, with the per centage of people agreeing with the statement showing an increase from the 1990s until 2008, before dropping again.

However, analysis of political rhetoric and public attitudes towards benefits between the late 1980s and 2015 seems to indicate that "shifts in public opinion occurred mainly in response to changes in the way that politicians have framed and discussed both the welfare system and its users over the past thirty years" (O'Grady, 2017, no pagination).   The biggest drop in public support for spending on unemployment benefits took place under the Labour governments of the late 1990s and early 2000s and when O'Grady tracked changes in political rhetoric about benefits during these New Labour years he found that the change in social attitudes followed the changes in political rhetoric, leading him to conclude that "the large reversal in public support for benefits can only be explained as a reaction to the discourse of politicians, filtered through the media" (Ibid).

The most striking thing across all the surveys of British social attitudes, is that - although there are variations across time of attitudes towards spending on both disability benefits and on unemployment benefits - the British public are much less likely to support expenditure on people classified as 'unemployed' than those classified as 'disabled'. There is therefore much more likely to be support for government policies which, for example, seek to reduce work incentives by reducing benefit levels, or increase conditionality attached to benefit receipt if people are classified as 'fit for work' or partially fit for work, and if they are considered not to be 'really disabled'.

The greatest increase in negative media coverage of benefit recipients in general occurred in the late 1990s and early 2000s (Baumberg et al, 2013). The extension of this negative coverage to disabled people occurred a bit later, during the time that the Labour government published its policies on reforming IB and replacing the Personal Capacity Assessment with the Work Capability Assessment and was well established by the time the Coalition government took office in 2010. An analysis of news media coverage of disabled people between 2004 and 2011 found an increase in stories about disabled people and benefit fraud, with pejorative language used to describe disabled people and in articles presenting disability benefits as a burden on the economy (Strathclyde Centre for Disability Research and Glasgow Media Unit, 2012).

Research on benefits stigma carried out in 2012 found that, although there remained widespread over-estimation amongst the public about the level of benefit fraud, media coverage was now more likely to refer to "lack of reciprocity and effort on the part of claimants than they were previously" (Baumberg et al, 2013, p.80) and that a key criteria for achieving a 'deserving' status was "the level of responsibility that claimants were seen to hold for their own situation" (p.79). When Valentine and Harris carried out research examining how people define certain groups "as less worthy of moral consideration than their own" (2014, p.84) they found:

> people from across the class spectrum hold prejudices towards those who do not work (so-called 'skivers') because dependency on welfare is perceived to be self-inflicted: a product of personal choice (e.g. not to engage at school, not to take low-paid work) and/or a lack of self-discipline (p.89).

The research concluded that these powerful narratives about dependency, used to distinguish between the 'deserving' and the 'undeserving' were now also being mobilised in relation to disabled people with participants stressing:

> the need for disabled people to make a contribution to society where possible (e.g. by undertaking paid work) rather than being dependent on welfare benefits, and stressing the importance of disabled people taking responsibility for their own lives rather than deserving 'special treatment' from the State (p. 89).

O'Grady's analysis (mentioned above) suggests that political rhetoric influences public attitudes, rather than the other way around and, in this context, the type of language Labour politicians used as they developed the welfare reform agenda which resulted in the replacement of IB with ESA is significant. For example, in a 2006 speech, Secretary of State John Hutton argued that "Our welfare reforms must confront head-on the "Can work – won't work" culture in our country" and that "We cannot reasonably ask hard-working families to pay for the unwillingness of some to take responsibility to engage in the labour market" (Hutton, 2006, no pagination). Piggott and Grover (2009) identified both government and media giving the message that the Incapacity Benefit

system was making some people unnecessarily 'dependent'. The Green Paper published in 2007, *A New Deal for Welfare* opened with the contention that "Benefits trap people into a lifetime of dependency" (Department for Work and Pensions, 2007a, p.4) and aimed to "reduce by 1 million the number on incapacity benefits" (p.3). Newspapers and broadcast media similarly focussed on this supposed unnecessary 'dependency', backing up the government's message that many people need not be relying on IB (Piggott and Grover, 2009, pp.162-163). This contention was driven home by the Secretary of State for Work and Pensions who issued a press release announcing the introduction of the WCA, referring to the "drive to end sick-note Britain" and claiming that "Fifty per cent of those who take the assessment will not pass it" (Department for Work and Pensions, 2007b, no pagination).

The neoliberal assumptions of people as 'rational actors', driven by self-interest, was key to both the political justifications for welfare reform and the public representation of people reliant on income replacement benefits because they could not sell their labour power. Such rhetoric became stronger after the Coalition government came into office in 2010 with the media (both broadcast and newspapers) playing a key role in representing the financial crisis of 2008 as the result of irresponsible government spending, and 'austerity' being presented as an imperative (Blyth, 2013). As part of this narrative, politicians talked about the need to address the issue that some people were "choosing a life on benefits" (Cameron, 2012) and how adjustments must be made to the benefits system so that they would be incentivised to seek employment.

Negative attitudes towards benefit claimants have, as Katz argued (1989), acted as a form of 'labour discipline' - an incentive to avoid falling out of employment and onto benefits because of the associated social stigma. For many years following the expansion of the social security system after the second world war, this type of stigma tended not to be applied to disabled people. Instead, they were more likely to be assumed to be inevitably dependent on the State and their families as a result of their impairments (Barnes, 1991). The reforms to out-of-work disability benefits which started in the early 1990s gradually saw similar levels of suspicion and stigma applied to those in receipt of such benefits that previously had been reserved for the

'undeserving unemployed'. The influence of this shift in public and political attitudes is, as we shall see, apparent in disabled individuals' experiences of the Work Capability Assessment, the validating device by which the State distinguishes the 'deserving' from the 'undeserving'.

Conclusion

Reform of out-of-work sickness and disability benefits under Labour, Coalition and Conservative governments has been based on the assumption that incapacity to work can be measured objectively. This contention has underpinned each assessment process since the introduction of the All Work Test in 1994 when the argument was that doctors appointed by the Department for Social Security would be more 'objective' than applicants' GPs.

Posing an 'objective' assessment against an individual's own assessment of how their health or disability affects them, combined with a failure to focus on demand side factors, can lead to an implicit, and sometimes explicit, judgement that being unable to get employment is the individual's fault and that they are therefore undeserving of support from the taxpayer. When this is tied to the idea that paid employment is how people contribute to society, those who are not in paid employment are increasingly seen as making a choice not to do so, specifically a choice at the expense of the rest of society.

In Stone's analysis of disability as an administrative category, those determined as disabled and 'deserving' of state support are also considered 'innocent' and 'suffering' (Stone, 1984, p 172). Innocent in that their impairment/illness is seen as beyond their control, and suffering in that this impairment/illness is to be pitied and causes a form of incapacity which means they are unable to work. This puts disabled people judged as unable to work at a higher 'moral' status than those just deemed as unemployed. As successive governments have wanted to reduce the numbers on, and the costs of, long-term out-of-work disability benefits they have needed to adjust who is considered 'deserving' of this support. This dilemma is clearly being played out in the two different groups who make up those in receipt of Employment and Support Allowance. Those deemed 'the most vulnerable' and 'deserving' got the protection of the Support Group, whereas those in the Work Related Activity Group are increasingly being viewed as the same as those claiming Job Seekers'

Allowance - the potentially undeserving unemployed, who are obligated to make themselves available to be pulled into the labour market (and thus part of the active reserve army of labour).

Where the 1990s saw the replacement of unemployment benefit with Job Seekers' Allowance and the tightening of eligibility criteria, means testing and increasing expectations on those claiming unemployment benefit, the same approach has now been applied to many disabled people. In the process, those to whom this approach is taken are being categorised as 'not really disabled'. The separation of out-of-work disability benefits into two distinct groups - the Support Group and the Work Related Activity Group - has been followed by increasing obligations placed on those in the WRAG, the introduction of means testing after 12 months and the £30 reduction in payments compared to the Support Group introduced in 2017. This and the WCA itself have changed the perception of who is deserving of being exempt from waged labour, to mean that a larger number of people, whose impairments and/or health condition impacts on their employment opportunities, are now viewed in the same way as those non-disabled people claiming unemployment benefit. This means that some disabled people are now moving into a category which, as the analysis of the social attitudes surveys show, is a largely unpopular policy priority and as such allows governments to further cut support. The question must be asked as to whether we are on a path to the disappearance of the WRAG category altogether, a development which, depending on the next stage of policy development on a validating device may well result in a significant reduction in who is officially categorised as disabled.

Chapter 2 argued that this tightening up on eligibility for out-of-work disability benefits has been fuelled by a desire to recommodify disabled people's labour in order to pull them into the active reserve army of labour. Someone who is defined as 'fit for work' rather than eligible for ESA is, technically, available to the labour market, while a person in the Work Related Activity Group is subject to interventions which are intended to make them 'work ready'. The latest stage of welfare reform (the 2017 *Improving Lives* White Paper, further discussed in Chapter 8) is trying to engage the 1.5 million people in the Support Group in ways which will, it is hoped, move them closer to the labour market, such a

policy becoming more urgent because (as pointed out above) this group (the 'stagnant surplus' who are not required to be available for work) is now larger than had been originally intended.

Governments have been motivated to develop and implement policies to pull disabled people into the labour market as a way of bringing down, and keeping down, the level of inflation and of public expenditure. Nevertheless, as Chapter 2 argued - and as the failure to reduce the numbers on long-term benefits has demonstrated - there is a limit to which disabled people can be pulled into the active reserve army of labour. Indeed, the current direction of travel of the labour market - the increase in low paid, insecure, low control, high effort jobs - means both that disabled people are less likely to be recruited to such jobs and, moreover, that such working conditions are increasing the levels of 'common health problems' amongst the existing labour force. The structure of the labour market is such that there are diminishing employment opportunities and, in addition, there are an increasing number of jobs the characteristics of which often have a disadvantageous impact on people's physical and mental health. This is the material reality facing disabled people, a reality which, as we shall see in Chapter 5, was largely ignored in the context of the development and implementation of the current validating device, the Work Capability Assessment.

Chapter 4: Research Methods

Introduction

This chapter discusses the research design and process, looking at what the methodological and theoretical underpinnings were to the research, and what and why particular research methodology and methods were chosen. It will then go on to discuss how the research process unfolded, before reflecting on this process and the challenges and difficulties encountered. The final section of the chapter discusses the two-pronged approach to analysing the data generated.

The thesis of this research is that a disconnect exists between the administrative category of disability (as defined in the context of determining eligibility for out-of-work disability benefits) and disabled people's lived experiences, and that this disconnect is created by the position of waged labour in neoliberal capitalist economies. The previous chapters have examined the changes in the mechanisms used to create this category, and how these relate to changes in the labour market. It was then necessary to understand, firstly how the current validating device, the Work Capability Assessment, was developed to take the particular form that it does; what disabled people's experiences are of the WCA; and how their lived experiences compare to the theoretical and ideological assumptions which underpin it.

This chapter discusses the approach to the analysis carried out of six documents which were key to the development of the WCA (which is the subject of Chapter 5); and the methodology used to carry out primary research on disabled people's experiences of the WCA (the results of which are discussed in Chapters 6 and 7).

4.1 Documentary analysis

Jennifer Mason suggests various ways in which documents may be the subject of research and analysis: they could be "meaningful constituents of the social world in themselves"; the "processes by which they are produced or consumed" may be the focus; it may be believed that "they act as some form of expression or representation of relevant elements of the social world; or it may be that "we

can trace or 'read' aspects of the social world through them" (Mason, 2002, p.106). During the course of examining the history and development of the validating device which is the subject of this thesis, six documents were identified (described in Chapter 5) which, I would argue, are potentially of interest and relevance in that they merit analysis for all of the reasons that Mason identified.

These documents trace the course, over forty years, of an approach to impairment and illness which started off in one particular medical discipline, was taken up within another, further developed to influence a number of professions and disciplines concerned with determining eligibility for out-of-work disability benefits (both in the private and public sector), until finally it was, and remains, at the heart of government approaches to determining whether disabled people should be exempt from selling their labour. In examining these documents I am attempting to "elicit meaning, gain understanding, and develop empirical knowledge" (Bowen, 2009, p. 27). By analysing them, I have sought to understand the frame of reference by which their conclusions are generated. However, I am also applying my own frame of reference to my reading of the documents and I have therefore interrogated them using the social model of disability. I also seek to place them in the context in which they are generated, some of which has already been covered in Chapters 2 and 3, and my analysis is informed by the theoretical approach as set out in Chapter 1. While the focus of the documentary analysis is on the ideas which inform and determine the nature of the Work Capability Assessment, it is the material reality which generates the requirement that the validating device takes the form and content that it does.

This documentary analysis serves as a key part of understanding both the nature of, and the reasons for, the experiences of disabled people which were gathered using the methods set out below. The analysis is thus key to understanding what the WCA is validating (or invalidating), how disabled people experience the assessment and its relationship to disabled people's experiences of both impairment and disabling barriers.

4.2 Gathering data on disabled people's experiences

The two questions the primary research aimed to answer were:

- How did disabled people experience the Work Capability Assessment?

- How did the experience of this assessment relate to their own perception of limitations on their capacity to sell their labour?

As the research progressed a number of secondary questions arose, which will be discussed below.

In order to gather data on what these experiences were two types of qualitative research methods and one mixed qualitative/quantitative method were chosen. Before discussing how these methods were put into practice it is necessary to set out the methodological approach underpinning them.

4.2.1 Emancipatory research

The methodological approach and methods used were both guided by the aim that disabled people's lived experience should be a central part of the research. As these experiences, and whether they are disconnected from how those in political power perceive them, are central to this research it was important that the research did not replicate this power imbalance. Disability research not only has a history of perpetuating disabling hierarchies and oppression (Hunt, 1981; Morris, 1992; Oliver, 1992; Stone & Priestley,1996) but of being viewed as a violation of disabled people's lived experiences (Oliver, 1992). In response, the disabled people's movement has developed the paradigm of emancipatory research.

Emancipatory disability research emerged as part of the critical theory approach to social research (Barnes and Mercer, 2004, p. 53), which signified a rejection of the dominant paradigms of social research which were positivist and interpretive. The positivist paradigm implied that "the social world could be studied in the same way as the natural; that research could be 'value-free'; that the knowledge and causal explanations obtained would be independent of the methods used or the beliefs of the researchers involved" (Ward and Flynn, 1994, p. 30). Research following this approach tends to view disability as an

individual and functional problem, with researchers focused on finding ways to measure, cure or prevent this functional problem. This means the unit of analysis is the individual and the point of intervention is the individual condition (Rioux, 1997). When research centres disability in a medical and individual way it can only conclude that any problems experienced by disabled people are located within the body of each individual. This then leads to research findings which fail to understand the social and political dynamics which impact on people's lives and goes directly against the understanding of the social model of disability, which this research was underpinned by (see discussion in Chapter 1).

The interpretive paradigm had challenged some of the assumptions of the positivist approach by arguing that "all knowledge is socially constructed; the social world differs from the natural in that those studied are active participants not passive objects" (Ward and Flynn, 1994, p.30). This led to the conclusion that "research should try to understand the meaning of events, not just their causes" and that "knowledge and understanding obtained from research will be influenced by the researchers' values and are not independent of them" (Ibid). However, social model researchers felt this still failed to fully acknowledge and understand disability as a political issue and replicated some of the problems with positivist research which saw the researcher hold all the power. Too often this meant that the person and organisation carrying out the research derived more benefit from it than the passive research subject (Oliver, 1992, p.109).

Emancipatory research aims to challenge the positivist paradigm by arguing 'knowledge' cannot exist in a vacuum uninfluenced by culture and society (Mercer, 2004). Instead of claiming objective neutrality, emancipatory research acknowledges that when "carrying out research we inevitably draw from our social, cultural and historical background at all stages of the research process" (Rooney, 2005, no pagination) and argues that this can be used as strength, not as a disadvantage. It also aims to actively work to change the social relations of research and use research to confront and challenge the oppression disabled people experience (Oliver, 1992, p.102).

Oliver points to three ways in which research had failed disabled people:

It failed to accurately capture and reflect the experience of disability from the perspective of disabled people themselves.

It failed to provide information that has been useful to the policy making process and has contributed little to improving the material conditions under which disabled people live.

It failed to acknowledge the struggles of disabled people themselves and to recognise that disability is not simply a medical or welfare issue, but a political one as well (Oliver, p. 2, 2002).

These three critiques also underpin my approach to research. I believe that those who the area of research is about are the experts on their lives and the most important people to listen to in order to understand a subject. I also believe that research should aim to contribute something towards improving the material conditions under which those at the centre of the research live, and that disability is very much a political issue.

4.2.2 Approach to this research

One of the first things it is important to do is lay out my social, cultural and historical background and how it might impact on the research. As a disabled woman myself, and one who grew up with a disabled mother, my lived experience of disability had an impact on all stages of the research. My personal experience was particularly relevant as I have been subject to assessments for both Incapacity Benefit and Employment and Support Allowance, and experienced long periods on out-of-work disability benefits, as well as facing barriers to achieving and sustaining employment. I found that this personal experience was vital on several occasions to be able to gain the trust of participants who, due to their experiences with both researchers and those involved in benefit assessments, were initially wary of taking part. It is this lived experience, combined with my previous research during an MA in Social Research, which led me to believe the research was required.

My research for the MA dissertation looked at the impact of welfare reforms between 2010 and 2012 on disabled people in the UK. The findings suggested that assessors of eligibility for disability related benefits lacked "understanding

and knowledge" about impairments or ill health and that the WCA was "highly inaccurate in determining fitness to work" (Morris, 2013, p. 725). The experiences of disabled people reported in that research pointed to a potential disconnect between the administrative category of disability and disabled people's lived experiences of disability and impairment. However, it did not explore the underlying reasons for this disconnect, and this, therefore, has been a key focus for my PhD research.

One of the key arguments of emancipatory research is that "established social relations of research production give rise to inequalities of power between researcher and researched" (Priestley, 1996, p.88). Like increasing numbers of researchers in the field of disability, I was seeking to carry out research which did not replicate these unequal power relationships. Emancipatory research aims to change the social relations of research production (Barnes, 2001) and challenge social structures which disadvantage disabled people (Barnes and Mercer, 1997). Although no one piece of research can ever do this in and of itself, I wanted my research to add to previous research which is working towards this goal.

There were, however, limitations on the extent to which I was able to meet the requirements of Emancipatory research, particularly the aim to be accountable to the disability community and to enable disabled people to have more control over the research agenda and research processes. My ability to fulfil this principle was limited by my accountability to both the university and to the funding body, the Economic and Social Research Council (ESRC). Indeed, it has been suggested that "It may be that university regulations prevent students from adopting this model of research" (Seymour & Garbutt, 1998, p.3). It was also limited in part by my own impairment when it comes to interactions with other people, something that is discussed in more detail in the reflective part of this chapter.

However, as the focus for the research followed on from my previous research with a disabled people's organisation (Morris, 2012), and as I consider myself a disabled person, I hope that this has prevented the research agenda having been determined by total 'outsiders'. Although, as noted by Barnes, "having a

designated impairment does not automatically give someone an affinity with people with similar conditions or disabled people generally" (Barnes, 2001, p.10). Whilst acknowledging and taking this into account I hope that having had direct experience of the particular topic and the fact that disability activists and organisations have also identified the research topic as being of current crucial importance to disabled people (see for example, Spartacus, 2012 & 2013; Disabled People Against the Cuts, 2013; Hale, 2014) gives the research more chance of being helpful rather than harmful to disabled people. In addition, although I cannot be accountable to the disability community in general, I have aimed to be accountable to the research participants, with all methods and data analyses open and fully explained to all involved and the dissemination of the research will be available to all.

One thing it was important to remember throughout the research was that disability is not a homogeneous experience (Stone & Priestley, 1996) and it is unrealistic to expect that any research can represent all disabled people's lived experiences. This is something which is taken into consideration when discussing the data generation methods that will be used.

4.3 Data collection and participant recruitment

The three data collection methods used were focus groups, individual interviews, and an online survey. This meant that both quantitative and qualitative research methods were used. However, as will be discussed below, despite a survey traditionally being a quantitative method (Wolff et al, 1993; David De Vaus, 2013) the amount of data generated by the open-ended questions provided some very rich qualitative responses.

The use of qualitative methods was important as they enable people's voices to be heard by giving the space for expression and exploration of experiences (Barton 1999) and qualitative data helps provide "a rich understanding of people's lived experiences and perspective" (Freeman, 2006, pg 491), something that was paramount to this research. As Jennifer Mason (2002, p.3) states, qualitative research is "concerned with how the social world is interpreted, understood, experienced, produced or constituted" and so this

approach has been an essential part of understanding how disabled people experience the WCA.

However, there are several common criticisms of this type of research that it was necessary to consider. Silverman identifies these as reliability, anecdotalism and validity (Silverman, 2014, pp.22-23). All of these potential problems arise from the fact that qualitative research methods, such as focus groups and face to face interviews, are typically focused on a much smaller sample size than quantitative methods. One way I tried to address these concerns was through the online survey, which allowed me to gather the experiences of many more people than focus groups or interviews alone would have allowed. Although I would argue that every participant's experience was valid in its own right, the survey allowed me to expand and explore whether the experiences discussed by the focus groups and in the individual interviews were more commonplace, and as such increase the reliability and validity of my conclusions of the assessment process as a whole. As has been argued, combining these two methods can "enhance the quality of the resulting analysis and the confidence that can be placed in it" (Wolff et al, 1993, p 119).

The next part of this chapter will discuss the sampling and recruitment process for the focus groups and interviews, before going on to explain how the data gathered from these informed the survey questions and approach.

4.3.1 Focus groups and interviews: rationale

Both focus group and individual interviews have proved to be effective in both gathering people's experiences and enabling participants to have some control over how data is generated (Wilkinson, 1999). This means that research is more likely to be influenced by what respondents feel to be important, by their own "language and concepts" and by their framework "for understanding the world" (Kitzinger, 1994, pg.106). Research participants have also reported that being involved in a focus group can be empowering in itself as it gives people an opportunity to share their experiences with others (Wilkinson, 1998).

It is also argued that the collective discussion, the "probing as they meet one another's disagreement", which are features of the focus group method, "will do more to lift the veils covering the sphere of life than any other device" (Bulmer,

quoted in Flick, 2006, pg 191). Such discussions help to create better understanding of specific experiences, prevents the discussion being limited by the researcher's knowledge or perspective, and means that participants have more influence over how and what data is generated (Kitzinger, 1994; Morgan, 1997). They achieve this by allowing participants "to generate their own questions, frames and concepts and to pursue their own priorities on their own terms, in their own vocabulary" (Kizinger & Barbour, 1999, p. 5). Group discussions also help to avoid approaching disability and impairment as solely individual experiences (Kreuger, 1994; Morgan 1998, ref in Smithson, 2000) and help to ensure the research takes a social model rather than a medical model approach. However, like all methods of research, it was important to acknowledge that focus groups can be "open to careless or inappropriate use", results can be manipulated, "and 'subjects' of the research exploited" (Kitzinger & Barbour, 1999, p. 2).

The individual interviews, although unplanned (see below), were able to compliment the focus groups very well by providing some more in-depth experiences than people taking part in the focus group may have felt comfortable sharing. One of them in particular also provided some crucial thoughts and perspective on how I might go on to both design and distribute my survey. They were used to help inform and direct the online survey, which not only helped with the specifics of questions and what was covered, but also countered some of the problems and limitations of surveys typically being unilaterally controlled by the researcher (Wolff et al, 1993; Morgan, 1997).

4.3.2 Focus group and interviews: sampling and recruitment

Due to the specific topic of the research, purposive sampling techniques were used to identify participants who matched the characteristics necessary to answer the research questions. These were people of working age (defined as 18-64) who have had experience of applying for out-of-work disability benefits. This was then narrowed further by wanting to prioritise people with particular impairments which either research has shown are usually marginalised, or are less likely to participate in the online survey, and who the literature showed were particularly likely to have difficulties with the government's validating devices being able to capture their lived experiences. These were then further

narrowed by wanting to work with disabled people's organisations (DPOs) to recruit and host the focus groups, which then brought in convenience and snowball sampling techniques, by recruiting those who had contacts with the DPOs and those who met the criteria who they had contact with. The benefits and limitations of these are discussed below.

I initially aimed to conduct four focus groups with an aim of prioritising those people whose voices are usually not listen to. Because of this, the first thing I did when starting to organise the focus groups was to make contact with an organisation that is run by and for people with learning disabilities/difficulties as not only are they more likely to be excluded from research in general (Walmsley, 2001) but they were also less likely to take part in the online survey part of the research. This first contact was made and a meeting held to discuss setting up a focus group in June 2014. However, despite continuing to try and make this focus group possible up until late 2016, it unfortunately never took place. The reasons for this were a combination of the initial person I had a contact with leaving the organisation, general confusion over what was required in order for the focus group to go ahead, my own struggles with pursuing people, and my second contact having to take sick leave.

I am very disappointed that this focus group did not happen as people with learning disabilities/difficulties are a group which is too often left out of research on disabled people's experiences generally. However, I did have twenty five respondents to the online survey who said they had "learning disabilities/difficulties", and, although I did not ask anyone at any of the focus groups to disclose their impairment, the organisation I worked with to set one of them up indicated that some of the participants had learning disabilities/difficulties. This does not make up for the fact that I was unable to do a focus group specifically with people with learning disabilities/difficulties, which may have given a more in depth understanding of how the administrative category of disability is particularly experienced by those with learning disabilities/difficulties. However, it does mean that were at least some experiences shared.

I do believe that it might be useful for future research in the same area to be done that is specifically related to how the labour market and the administrative category of disability impacts on people with learning disabilities/difficulties. Such research would be particularly important in the light of various suggestions from commentators, politicians and business leaders that people with learning disabilities/difficulties should be "allowed" to work for less than the minimum wage (Monckton, 2017, Field, 2017). There also needs to be research on the experiences of those who had been employed by Remploy in 'sheltered employment', until such workshops and factories were closed, as this would arguably add a particular depth to research concerning disabled people and capitalism. It would also enable some of those whose voices are usually silenced to be heard.

In the end I held two focus groups (one in Norfolk and one in London) and two individual interviews (both in London). These interviews had intended to also be focus groups but only one person was able to attend on each occasion. I worked with three different disabled people's organisations (DPOs), with two of them recruiting participants from their membership base and the third being a combination of different recruitment approaches.

A key limitation of recruiting only from those disabled people who were members or contacts of particular DPOs was that it narrowed the scope of potential participants. However, the fact people were already in contact with and knew those organisations also meant they were more likely to trust that it was safe to take part and, in addition, my previous research had illustrated that it was important that advice and support from an organisation was readily available for participants (Morris, 2012). The location of the focus groups and interviews was also important. It needed to be somewhere that people could both access relatively easily and an environment where they would feel comfortable discussing potentially difficult issues. So, by holding them at organisations and venues that potential participants were likely to already know and feel comfortable with this increased the chances of achieving this.

This method of recruitment meant I was using a non-probability sampling strategy, as my sample population would be chosen from those who were

'close at hand' (Punch, 2005). It also meant the method I used for recruiting them (the disabled people's organisation) was able - in two cases - to have more direct contact with potential participants and in practice it appeared this had a direct impact on whether people who showed interest in participating came on the day or not. Another potential benefit was that some of the participants knew each other prior to the focus group, something which can be an advantage when discussing personal experiences and helping participants feel safe and comfortable (Bloor et al 2000).

The third of the three organisations I worked with (a federation of London-based groups) was a lot larger than the other two and operated in a different way, something in hindsight I should have considered the potential pitfalls of. As it was a larger and broader organisation they had a lot less direct contact with their members, and this meant there were less 'close at hand' opportunities for recruitment. As this resulted in fewer people expressing an interest, I also then tried to find participants through the campaigning organisation Disabled People Against the Cuts (DPAC) because I was aware they were in contact with large numbers of people who had had Work Capability Assessments. This did create a lot of interest from people, but many of them were not based in London and were unable to attend the focus groups. However, it may have helped increase interest in the research overall and have provided more participants for the survey. The differing success rates between the two types of organisations and recruitment strategies shows the importance of gatekeepers and contacts in gaining the trust and commitment of research participants.

The first focus group was organised with a disabled people's organisation in Norfolk. I had decided it was worth trying to hold at least one focus group not in a large city location as the experience of claiming may be different in different areas of the country. Ideally it would have been particularly useful to do a focus group in an area where the numbers of claimants have previously been explained by the loss of industry and now may be explained by the long term economic decline and the impact that has on both general health and job availability for disabled people. However, due in part to limitations created by my own impairment (discussed further below), it was necessary to work with an

organisation I already had a contact with. Further research specifically focused on those regions may produce useful data to add to the understanding this research aims to provide.

I also wanted to make sure that those with mental health conditions and/or fluctuating conditions were included because, as mentioned in the previous chapter, there has been evidence that the WCA particularly struggles to understand how these impact on someone's ability to work (Rethink, 2013; Hale, 2014), which also reflects my own experience with the assessments. Also, as discussed in previous chapters there has been a significant increase in mental health conditions being the main reason for someone to claim disability benefits. So, when recruiting for my second focus group in London I made a flyer requesting participants who had particular experience of a mental health condition. Unfortunately, this was one of the focus groups where only one person attended. However, this did end up providing some in depth and rich data in the form of an individual interview. It also became clear from both the focus groups, the interviews and the survey that not only did a majority identify mental health as the main reason for their claim, but that even for those who did not, mental health and the impact of the assessment process was a major issue.

Despite having problems recruiting people for the focus groups held at the disabled people's organisation in London, it was after receiving information about these that another organisation contacted me and asked if I would be interested in holding a focus group with their members. This was a great example of networks and snowballing working to reach potential participants and arguably also was a demonstration of the research topic being one people wanted to talk about and contribute to.

4.3.3 Online survey: rationale

Following on from using Twitter as a recruitment method for my MA research I initially wanted to expand and extend how Twitter was used in this research. As a long term active twitter user, I had found it was a very useful tool for interesting debates and discussions and felt it could be used to enable a discussion around people's experiences at a much greater level than a

traditional focus group would allow. Part of the reason for this is the potential reach of Twitter, allowing not just more people to be involved in a discussion, but also people from many locations across the country, that the constraints and restrictions of travel, time, and expense would not allow in a face to face setting. I also felt the Twitter discussions would enable me to create questions for face to face focus groups, which would mean these questions would be more under the control of research participants, thus adhering to some of the principles of emancipatory research.

However, I eventually decided to do the research the other way round and use face to face focus groups to inform questions for an online survey which would be distributed via Twitter. Part of the reason for this was an ethical consideration around privacy and informed consent. The use of online forums and social media as a research method has forced researchers "to rethink and re-evaluate such fundamental research ethics issues as privacy, informed consent, ownership, recruitment, public versus private spaces, and research and scientific integrity itself" (Buchanan and Hvizdak, 2009, p. 37). Although an open Twitter discussion – i.e. one that is between accounts which are not locked (that is, visible to anyone rather than only visible to those given access to view them) – may be considered public (Townsend and Wallace, 2016) it must also be noted that "it is problematic for a researcher to justify their actions as ethical simply because the data are accessible" (Body & Crawford, 2012, p 672).

Although I planned to make it clear the discussion was part of a piece of research, if anyone taking part in the Twitter discussion had wished to remain anonymous when I came to writing up the research it would have restricted how I would be able to use their contributions. For example, if I had wanted to use a quote from someone on Twitter, that person's identity is searchable by the quote being linked to their Twitter account. So even if you use a quote without using someone's Twitter handle, if someone puts that quote into a search engine it will appear with a link to that person's Twitter account. As this would heavily restrict how I could use any data generated by the Twitter discussion, I felt that an online survey would be a better way to allow people to tell me about their experiences in an anonymised way that also did not leave

any potential for their contributions to be traced back to them in any way and also did not run the risk of people taking part in the discussion without realising it was for a piece of research.

I had previously used an online survey as part of my MA and found it very useful at obtaining rich data from a larger number of people than would be possible by just focus groups or individual interviews, and in particular I found the use of Twitter as a recruiting tool (discussed further below) can be very successful.

Despite surveys traditionally being more quantitative focused, this previous experience had shown how it was possible to use a survey to gain, not only quantitative data, but also - by using open as well as closed questions - some rich qualitative data in a low cost and efficient way. An online survey would also enable me to access participants who were unable to attend focus groups or interviews and potentially increase the validity of my findings by increasing the numbers of overall research participants. By using the survey, rather than Twitter discussions, I could overcome potential issues of anonymity and informed consent by all responses being anonymous and every participant having to confirm they had read and understood the information page about the research before beginning the survey. I was also aware that using an online survey had to overcome the problem of less interaction and clarification between researcher and participant, which can lead to misunderstandings of questions. I tried to minimise this by asking anyone with any questions regarding the survey or research to email me. Using Twitter as a main way of recruiting participants also helped with this as anyone could also contact me via Twitter with any queries.

Again, following on from my previous experience of using this method, I wanted to include a fair amount of open ended questions that would allow people to talk about their experiences at length, but I also realised that not everyone would be willing to do this and decided the best approach was to include the open ended questions as additions to more closed questions, which would also enable quantitative analysis. Using data generated by the focus groups and interviews I decided to spilt the survey into different sections asking about

people's experiences of the form, the assessment itself, both with additional parts and places to elaborate in detail about their experiences, and then a section about what people felt were their main barriers to paid employment, and finally some demographic questions. Using the Bristol survey tool to host the survey meant I was able to design a multipage survey and also meant I was able to use their analysis tools to very quickly analyse the quantitative data.

4.3.4 Online survey: Sampling and recruitment

As with the focus group and individual interviews, the sampling frame for survey respondents was people between 18 and 64 who had experience of applying for ESA. A snowballing method was also used but on a much broader scale. I have over 5000 Twitter followers, which immediately offers opportunities for reaching a large number of potential participants, although of course the majority of these may not have experience of applying for ESA. So, in order to increase my chance of reaching potential participants I used hashtags which related to the research topic. This meant anyone clicking on that hashtag, regardless of whether they followed me, would see my tweets about the research, thus increasing the chances of reaching people who could participate. This is one way of targeting specific 'communities of interest'.

From my previous experience of using this recruitment method I knew that if I tweeted about the research when there was any news item or television programme about the research subject the response rate would increase. I also approached a number of different disabled people's organisations and disability activists on Twitter and asked if they were willing to share the survey. Both this use of gatekeepers and the use of Twitter as a recruitment tool helped to address some of the potential trust issues people may have had towards the research. Twitter allows for a more informal discussion and possibly makes it easier for potential participants to approach a researcher with any concerns. I also stated in the information about the research that I had direct personal experience of applying for ESA, which I hoped also went some way to reassuring people that they might be able to trust me and the research.

The survey ran for four months between April and August 2016. In total there were 330 respondents. At the start of the research I decided to aim for 100

respondents, so was both surprised and felt privileged to have over three times that target in the end.

4.4. Ethical considerations

There are a number of ethical considerations raised by this research, not just during the gathering of information about disabled people's experiences but also at the writing up stage. I followed the principles of ethical research set out by the ESRC (2010) and submitted and gained ethical approval for my research from the University.

I paid particular attention to accessibility, informed consent, confidentiality, and avoiding harm.

4.4.1 Accessibility

It was important that the focus groups and interviews were as accessible as possible. This was where it was again beneficial to be working with disabled people's organisations to organise and hold them, as it meant the venues were all accessible for any participants who had mobility impairments and I was working with people who understood how other access requirements might be met. This was particularly important when I was trying to set up the focus group of people with learning disabilities/difficulties as I worked directly with them to design an Easy Read version of both the information about the research, and also of the consent form. Although the focus group with this organisation ultimately fell through, it was very important to have done this as these Easy Read versions were then made available to members of the other focus groups. Participants were asked in advance about any additional needs they might have, for example if they needed information in large print or on tape, or if they had any particular communication requirements. I offered to pay for any personal assistance, transport or other costs incurred by participants to allow them to access the focus groups/interview. Accessibility was also a factor in the direct running of the focus groups, meaning it was important to allow and ensure that everyone got to contribute and to be very conscious that people could be discussing issues which may cause anxiety and/or distress and that some people may be less confident or comfortable sharing their experiences. I attempted to mitigate any of these problems by firstly making it very clear at the

beginning of each focus group or interview that anything that was said within them should be treated with respect and confidentiality, that any quotes from them used in the research would be anonymised and if at any time they wished to leave or to stop sharing that was absolutely fine. It was also important to be aware of any dominant voices and whether anyone was not getting an opportunity to share their experiences and if so to make sure I asked directly if they wished to.

The survey presented a larger accessibility problem, with the major one being access to the internet – which is discussed in further detail in the section below on limitations of the research. In terms of the survey itself it was hosted by the Bristol Online Survey (BOS), a website which follows the Web Content Accessibility Guidelines, and I also followed the advice given by the BOS on how to create an accessible survey.

4.4.2 Informed consent

Informed consent was established with participants in a number of ways:
• full written information was provided when people were invited to participate, with a contact email address for any queries
• focus group participants and interviewees were informed both in advance and on the day that they could withdraw from the group or interview at any point
• participants were informed that they could ask that their responses were not included in the research, should they have second thoughts about their participation. However, a time limit was imposed of three months after the focus group/interview took place
• participants were informed about what would be done with the information they provided
• focus group and participants and interviewees were asked to sign a consent form
• online survey respondents had to confirm they had read and understood the information about the research and agreed to participate prior to being able to take part in the survey.

4.4.3 Confidentiality

Participants were assured that all information provided would be anonymised. The information which was sent to organisations to distribute asking for focus group participants stated:

> All participants' details will be kept anonymous and you will be able to withdraw your consent at any time before or during the focus group and for up to 3 months after participation. All focus group participants will be asked to respect other participants' confidentiality.

The information that participants had to confirm they had read prior to answering the survey stated:

> All answers are confidential and anonymous. No information will be shared with any other individual or organisation and when writing up my research I will ensure that no respondents can be identified. None of the questions are compulsory and you can save the survey to complete at a later time at any point.

4.4.4 Avoiding harm

The subject matter of the research meant that people often found describing their experience of the WCA to be distressing. This was apparent not only in the focus groups and interviews but also from what the respondents to the online survey wrote in their answers to some of the open questions. My experience of carrying out research for my MA, with the involvement of a local disabled people's organisation, had shown how important it was to have specialist advice and support available. For example, when carrying out a focus group for that research someone from the organisation concerned came into the room, after the discussion, to offer advice or support. This was something that two of the organisations I worked with for the focus groups and interviews offered, however it was not possible for the third one. This was a failing on my part and something that should have been established with the

organisation in advance and I believe this support should ideally happen each time when running focus groups or interviews for this type of research.

Avoiding harm is a principle which has to be borne in mind throughout this type of research, and this includes during the writing up and dissemination. Proponents of emancipatory research have identified, as discussed above, that disabled people have too often found that research has been harmful in both the way it portrays disabled people and in the policies which have resulted. As the Social Research Association's Guidelines state, "social researchers must be sensitive to the possible consequences of their work and should as far as possible, guard against predictably harmful effects" (Social Research Association, 2003, p.17). Out-of-work disability benefits have become and remain a very contentious issue, with negative stereotyping being a common media representation (as discussed in Chapter 3) and with much talk about 'welfare dependency'. My approach throughout this research has been dominated by an over-riding need to avoid causing harm to the group of people from whom my research respondents have been drawn.

4.5 Reflecting on methods used

4.5.1 Limitations and lessons learnt: focus groups and interviews

A key lesson from my previous use of focus groups when doing my MA dissertation was that close contact was required with organisations helping to recruit participants. This was also borne out by the experience of this research in that where I had difficulties making and maintaining contact, this had a negative impact on the numbers attending and, in the case of people with learning disabilities/difficulties meant that I was not able to convene a focus group at all. One of the participants in the individual interviews spoke about how scared people were about talking about their experiences of the research topic, something which may have made the focus group recruitment harder. It was significant that the two successful focus group involved smaller disabled people's organisations who had regular contact with most of the people who attended the focus groups. This meant there was an established level of trust, which may have helped ease any concerns people had about taking part in the

research. So, in future research it is important that I consider what can help encourage trust, including whether disclosing my own experiences more might be useful. During the interview where this fear of talking about experiences was mentioned I did disclose my personal experience and this definitely had an impact on how much they were willing to share. I also received invaluable feedback about disclosing this when asking people to complete the survey.

The barriers to building close contact and involvement from the organisations concerned related not only to the organisations themselves but also to limitations created by my own impairment.

In terms of the first type of barrier - potential organisational barriers - two factors are relevant for any researcher who approaches an organisation for assistance in recruiting participants to their research. These are the closeness of the researcher's subject matter to the organisation's priorities; and the resources available to the organisation.

My subject matter was of great interest to all the organisations I attempted to work with, although it is perhaps the case that research on people's experiences of the WCA was not high on their agenda. However, all of the organisations were struggling in terms of resources - to varying degrees - given that the last few years have seen a reduction in grant funding generally available for local disability organisations, with a greater reliance on service contracts. The funding of the learning disability/difficulty organisation I was in contact with comes almost entirely from the consultancy and other work that they do and, although I was offering to pay for their assistance, other more substantial work quite rightly took priority.

In terms of the barriers created by my own impairment, I was unfortunate in that the period during which I had planned to do the focus groups coincided with an episode of severe depression and increasing social anxiety. This meant that simple tasks such as approaching organisations and individuals became incredibly difficult. I also had a massive panic attack at 4 am the morning of the first focus group and was convinced I was not going to be able to run it.

I attempted to mitigate the impact of my mental health difficulties by recruiting the help of a friend, who both assisted me to make necessary phone calls/emails to set up meetings and also accompanied me to the focus groups/interviews. Without this assistance I would have had to cancel the first focus group because of my panic attack.

I also found writing a detailed script for both introducing myself and the research, and for the questions and potential problems I may encounter helped. I still believe, despite this, that my anxiety impeded some of the discussions and wonder in hindsight if I would have been better off explaining my problems at the start of the research – which also could have acted as a way to tell participants that I also had experience of applying for IB/ESA. These difficulties did ultimately mean I did not carry out as many focus groups as I would have liked and limited the locations where they were held. For example, I have a long history of problems with insomnia, something made a lot worse when sleeping away from home. This meant that travelling to different locations was very hard and it was also harder to arrange for a friend to travel with me if I had managed to arrange focus groups in other locations and this presented yet another barrier to conducting them. At the time I was very concerned about how this would impact on my research overall. However, the volume and depth of the responses to the online survey produced greater and richer data than I could have ever expected.

4.5.2 Limitations and lessons learnt: online survey

The larger than expected number of responses and the detailed accounts produced by the survey were incredibly helpful in addressing some of the problems I found with arranging and conducting the focus groups. However, this method of data collection was not without its own problems.

One of the fundamental problems with an online survey as a research method is it immediately excludes those without access to the internet. In the year the research took place (2016) 25 per cent of disabled adults in the UK had never used the internet (ONS), and research comparing household internet access between those with disabled members in them and those without found that only 60 per cent of households with a disabled person had access at home to

the internet compared to over 80 per cent of households with no disabled people (Scholz, Yalcin, & Priestley, 2017). This means that any form of online research will not reach a significant proportion of disabled people. It also means that the sample is self-selecting rather than representative of the overall population who apply for ESA. One way of cross checking my findings was by comparing the demographics of participants to the demographics of ESA claimants. Although the age breakdown of participants largely reflected the age breakdown of ESA claimants, the gender and geographical location of respondents differed from the national statistics on claimants, with both women and London over-represented in the survey respondents.

There is also a problem with sample control for online research. As Simsek and Veiga (2001) note, "not only can people outside the population of interest respond to the survey, but also multiple responses from a single individual are possible" (p 223). One way I tried to prevent anyone from outside the population of interest from responding was having firstly a cover page outlining the research subject that participants had to confirm they had read, and then having specific questions about if someone had completed the ESA50 form to apply for ESA and then if they had attended a face to face assessment. These came before questions asking participants to elaborate on their experiences and aimed to ensure no one who did not have experience of them completed that part of the survey. However, when reading through the responses it became clear that someone had completed the survey who not only did not have experience of applying for ESA, but who was based in the United States. This is where the use of the Bristol survey tools allowed me to connect all answers from that person and remove them from the analysis. This does not mean that that person was the only participant who was replying without experience of applying for ESA though and it remains a drawback on online surveys that it is impossible to verify the respondents are either who they say or that they fully understand the research.

This is a drawback to all online surveys and also one of the limitations to using twitter as a recruitment tool. As Sloan (2017) discusses it is near impossible to gather truly accurate data on who uses twitter as twitter does not require any demographical information when signing up for an account – and even if they

did there is no way of ensuring it would be accurate. This means the most accurate data is likely to come from wider population surveys, which are aware of who exactly is taking part and using sampling techniques aimed to best reflect the general population. Research on twitter demographics using both the British Social Attitudes survey and the British Election Survey, conclude that those that do use twitter are more likely to be younger, more likely to be male, tend to be more educated, tend to be more politically 'attentive' and vocal than the general population, tend to be more politically liberal, and are more likely be Labour voters (Sloan 2017; Mellon and Prosser, 2017). One of the reasons twitter users may tend to be more politically 'attentive' than the general population is twitters use as a campaigning platform. These will all have had an impact on my survey sample and must be taken into account in the conclusions made about the data. For example, it is worth considering that those that are more politically 'attentive' or vocal and more likely to vote Labour may be more likely to consider policies implemented by a Conservative government as unsatisfactory.

Despite these drawbacks, and acknowledgement that my survey cannot be considered as fully representative of the general population of ESA claimants, receiving so many responses provided a large amount of rich data and many of the key findings reflect both the independent reviews of the WCA and other research looking at claimant's experiences (Spartacus network, 2012 and 2013; Hale 2014; Marks et al, 2017)

4.6 Analysis of the data generated

The fact that I am attempting to follow emancipatory research principles means that the data generated by the focus groups, interviews and online survey, needs to be read "not as accounts of 'personal troubles' but as evidence of 'public issues'" (Shah and Priestley, 2011, p.177). At the same time, I felt that it was important that participants felt that the research could be a way of communicating their lived experiences and therefore a way of 'making their voices heard'. This is particularly important as their voices are too often missing from policy debates concerning welfare and have certainly been missing from the thinking that resulted in the Work Capability Assessment (as is apparent from the analysis in Chapter 5).

These two considerations led me to carry out two analyses of the data. For the first, which is presented in Chapter 6, I analysed the data by themes which were generated by the responses of the participants. I used the structure of the online survey as the starting point for analysis but then identified the messages which emerged about those experiences. In other words, the text was categorised into three main sections - the experiences of the ESA50 form; the experience of the face to face assessment; and respondents' views of questions that might have helped identify factors which prevent them from being able to work and/or might make work possible. The first two categories were then organised according to positive and negative experiences, with each category then organised into sub-categories corresponding to the main messages contained within the data.

This first type of analysis was therefore what Mason refers to as a "literal reading" of the substance of the data generated by the focus groups, interviews and the open text in the online survey responses (Mason, 2002, p.78). This type of reading takes at face value what respondents said, although there are limits to which a purely literal reading is possible "because the social world is always already interpreted and because what we see is shaped by how we see it" (Mason, 2002, p.149). I am not claiming to be doing an 'objective' analysis of the text. I am bringing my knowledge of both the widespread criticism of the WCA and my own experience of the WCA to the analysis. However, while recognising the limits to an 'objective' reading of the data, it is important to recognise that the main messages were strongly and consistently expressed, and that they do reflect the findings of the independent reviews and other research. This 'literal' reading of the data generated is also an important acknowledgement of disabled people's own perspective on the experience of the WCA. As Priestley (1998, p. 85) argues, "A proper understanding of structural barriers and oppressive cultural representations is only possible when it is informed by the personal experiences of disabled people".

Chapter 7 approaches the data rather differently, in that it attempts to identify the 'public issues' revealed by the respondents' experiences. This chapter

therefore concerns an interpretative reading in that I am "involved in reading through or beyond the data" (Mason, 2002, p.149) to further understand the relationship that is being played out in the WCA process. In this type of reading I am interested in what the data tells us about what the WCA represents in that the data is being analysed in such a way as to illuminate firstly, how the WCA works to legitimate the state's role in determining whether someone is exempt from selling their labour on the grounds of impairment and/or illness and therefore entitled to a replacement income; and secondly, what the implications are for how disabled people experience the assessment.

Conclusion

This chapter has set out the design and process of carrying out the research, discussing the methodological and theoretical approaches. It covered what research methods were chosen and why, and reflected on the challenges encountered, including their impact on the research. As the final section of the chapter identified, two different approaches were taken to analysing the data generated by the focus groups, interviews and online survey, and these are the subject of Chapters 6 and 7. The next chapter, Chapter 5, concerns the documentary analysis of six documents which, it is argued, enable an understanding of the development of the theoretical and conceptual framework of the Work Capability Assessment. This chapter, therefore, sets an important context for understanding the experiences of those undergoing a Work Capability Assessment.

Chapter 5: The development of the theoretical underpinnings of the Work Capability Assessment

Introduction

Chapter 3 set out the changes in policy on out-of-work disability and sickness benefits since the 1970s, changes which culminated in the introduction of Employment and Support Allowance (ESA) and the Work Capability Assessment (WCA). As that Chapter explained, since the introduction of the All Work Test in 1994, eligibility for out-of-work disability benefits has been predicated on the idea that incapacity to work could be objectively assessed and each subsequent assessment - the Personal Capacity Assessment and the Work Capability Assessment - was claimed to be more objective than its predecessor. Each of these assessments was focused on functional limitations of the individual and none attempted any assessment of whether a person was actually likely to obtain employment within the local labour market, or consider how any barriers they may face could be mitigated.

A key feature of the validating device is that it is not just a mechanism for determining eligibility for an income replacement benefit. It is also grounded in an ideological framework which validates exemption from paid labour, conferring a social status of entitlement to publicly funded support. Chapter 3 described how policy, political rhetoric and attitudes about out-of-work disability benefits have shifted since the early 1990s. In order to understand disabled people's experiences of the process which determines their entitlement, it is important to interrogate its theoretical and conceptual framework and how this developed. This is the purpose of this chapter, which examines why and how the Work Capability Assessment takes the form that it does

While the WCA has arguably attracted heavier criticism and controversy than its predecessors, it is a culmination of ideas that were developed over a long period of time and which also influenced previous forms of assessment for out-of-work disability benefits. The purpose of this chapter is to explore - through analysis of six key documents - the development of the ideas which underpin the current approach to out-of-work disability benefits and, in so doing, explore how and why the WCA takes the form that it does. This sets the context for the

data generated by focus groups and the online survey about individuals' experiences of the WCA.

As Chapter 3 has described, since the early 1990s there have been a series of changes to the assessment for out-of-work disability/sickness benefits, each time driven by the belief that 'too many' people are qualifying for such benefits and that the assessment needed to be more 'objective'. A lot has been written about the way that a particular model of human behaviour - the biopsychosocial model (BPS) - was implemented in the introduction of the Work Capability Assessment in 2008 when Incapacity Benefit started to be replaced with Employment and Support Allowance (e.g. Jolly 2012, Shakespeare et al 2016). Research and journalism have also identified the links between those developing the ideas behind the WCA and the private insurance industry (Stewart, 2016; Rutherford, 2007). Shakespeare et al (2016) have closely examined the evidence base for the WCA, "revealing a cavalier approach to scientific evidence" (p.4) and concluding that far from being 'evidence based policy' it "offers a chilling example of policy-based evidence" (p.24).

My purpose is to add to this literature by carrying out an analysis of some key documents through which it is possible to trace the development of a way of thinking about illness and impairment which has profoundly influenced the State's response to claims of incapacity for work. I will argue that an examination of the ideas which influenced the development of the WCA reveals that while the BPS influenced their thinking, those involved also had criticisms of the BPS, arguing that it did not allow for individuals' adopting 'illness behaviours' of their own free will. By identifying and interrogating key documents, this chapter explores the origins of the BPS and how it - or rather a particular version of it - has been used in the development and implementation of the WCA. The chapter identifies how what was initially put forward as an argument for a more holistic approach to both psychiatric and physical illnesses became an assertion that what were designated as the 'common health problems' reported by many people receiving, or applying for, out-of-work disability benefits have little or no biomedical explanation. This approach then culminated in the assertion that 'disability assessment medicine' must acknowledge the possibility that 'illness behaviours' are driven by 'choice and

intent'. Finally, the chapter looks at how the approach was put into operation in the Work Capability Assessment.

5.1 Six key documents

This chapter presents an analysis of six documents (listed below) which, I will argue, are key to understanding how and why the WCA takes the form that it does. It is my contention that these documents are "meaningful constituents of the social world in themselves" (Mason, 2002, p. 106) in that they have influenced the development of the WCA; and also that "they act as some form of expression or representation of relevant elements of the social world" (ibid*)* in that they reflect what have become widely held views amongst both politicians and those responsible for carrying out WCAs and making decisions about eligibility. These documents are therefore key to understanding the experiences of people going through the Work Capability Assessment.

In analysing these documents I am seeking to understand the frame of reference that their authors were using but I am also applying my own frame of reference - the social model of disability (see discussion in Chapter 1) - to the documents. I begin by explaining why these particular documents have been selected, before interrogating them to explore the assumptions on which they are based and how they have influenced the current assessment regime for out-of-work disability benefits.

The documents are listed below, together with a brief explanation of their significance which is then further explored in detail in this chapter:

1. George Engel's 1977 article in Science which challenged both the dominant framework used in psychiatry and that used by some of its opponents (Engel, 1977). This document started the beginning of the journey towards the WCA in that it is an articulation of a way of thinking about illness and impairment (the biopsychosocial model) which influenced the development of what has become known as 'disability assessment medicine'.

2. Gordon Waddell's 1987 article in Spine proposing a 'new treatment model' for low-back pain (Waddell, 1987). Waddell worked in the

Orthopedic Department at Glasgow Western Infirmary. This article took the biopsychosocial model elucidated by George Engel and applied it to the treatment of low back pain. Waddell was later co-author, with Mansell Aylward of the work which set out the theoretical and conceptual framework of the WCA.

3. Mansell Aylward and John LoCascio's 1995 article in the Journal of Psychosomatic Research which proposed a new way of determining eligibility for disability benefits (Aylward and LoCascio, 1995). Mansell Aylward was at the time Principal Medical Advisor at the Department for Social Security while John LoCascio was a Vice President of US insurance company, Unum, who advised the British government on the design of the All Work Test. This article reflects a key stage in the development of a different approach to assessments for out-of-work disability benefits. It reveals the thinking behind the All Work Test introduced in 1994 when Incapacity Benefit replaced Invalidity Benefit.

4. A 2003 publication which contained the papers presented at a 2001 Conference on 'Malingering and Deception' (Halligan, 2003). The Conference was funded by the Labour government's Department for Work and Pensions, and attended by a DWP Minister, Malcolm Wicks and Mansell Aylward, then Chief Medical Officer for the DWP. The Conference brought together a range of people involved in the assessment of out-of-work disability benefits in the context of both the private insurance industry and publicly funded benefits.

5. The 2005 report, commissioned by the Labour government, which aimed to provide a 'scientific and conceptual' basis for assessing eligibility for incapacity benefits (Waddell and Aylward, 2005). Gordon Waddell was at that point an "independent consultant" and his work on the report was funded by the DWP's Corporate Medical Group. As we shall see, much of its thinking was reflected in both Labour and

Coalition government Ministers' speeches during the introduction and implementation of the Work Capability Assessment.

6. A further paper by Gordon Waddell and Mansell Aylward (Waddell and Aylward, 2010) setting out the 'models of disability' which formed the basis of assessments for both the Work Capability Assessment and the Personal Independence Payment (which replaced Disability Living Allowance) and which was used to justify the Coalition government's welfare reform policies. For example, the paper was distributed to all members of the House of Lords during their debates on welfare reform by Lord David Freud, Minister for Welfare Reform in the Coalition government of 2010-2015 (Freud, 2012, Col. 496).

5.2 The origins of the biopsychosocial model

In April 1977, George Engel published an article in *Science* arguing that psychiatry needed a "new medical model". His case was that the existing "biomedical model does not suffice to wholly explain disease" and that instead:

> To provide a basis for understanding the determinants of disease, and arriving at rational treatments and patterns of healthcare, a medical model must also take into account the patient, the social context in which he lives, and the complementary system devised by society to deal with the disruptive effects of illness, that is the physician and the healthcare system.

> (Engel, 1977, p.132)

This was an intervention in the debate amongst psychiatrists as to what extent, for example, schizophrenia was to be explained by "biochemical deviation", or whether psychiatry played a role in 'labelling' patients whose mental health condition was to be explained by family and wider social influences. Although in this 1977 article Engel was addressing the particular debate within psychiatry about the causes of mental health conditions, his argument was addressed to all forms of medicine. Psychiatry, he believed, was in danger of trying to emulate the restricted focus on biomedical explanations so dominant amongst other medical disciplines. He criticised the biomedical model for only allowing

two approaches to experiences of illness: the "reductionist" - in that "all behavioural phenomena of disease must be conceptualised in terms of physicochemical principles"; and the "exclusionist", in that "whatever is not capable of being so explained must be excluded from the category of disease" (*Ibid.,* p. 130).

In contrast, Engel argued it is not just biochemistry but a range of psychological and social factors that can influence how a person experiences conditions such as schizophrenia or diabetes and will influence, for example, how and when they "come to view themselves or be viewed by others as sick" (p.132). In discussing the "reality of diabetes and schizophrenia as human experiences as well as disease abstractions" he therefore identifies the need for a new model which does not give primacy to biological factors alone but also includes social and psychological factors. Applying this biopsychosocial model, he says:

> would make it possible to explain why some individuals experience as 'illness' conditions which others regard merely as 'problems of living', be they emotional reactions to life circumstances or somatic symptoms. For from the individual's point of view his decision between whether he has a 'problem of living' or is 'sick' has basically to do with whether or not he accepts the sick role and seeks entry into the health care system, not with what in fact, is responsible for his distress. Indeed, some people deny the unwelcome reality of illness by dismissing as a 'problem of living' symptoms which may in actuality be indicative of a serious organic process. It is the doctor's not the patient's responsibility to establish the nature of the problem and to decide whether or not it is best handled in a medical framework. Clearly the dichotomy between 'disease' and 'problems of living' is by no means a sharp one, either for patient or for doctor.

> (p. 133)

Engel was arguing that "the physician's basic professional knowledge and skills must span the social, psychological and biological, for his decisions and actions on the patient's behalf must involve all three" (p.133). He was not denying the relevance of biomedical explanations but decrying the reductionist and

exclusionist tendencies associated with the dominance of the biomedical model. Instead, in making the case for all three aspects of people's experiences, Engel was urging medicine to take a more holistic approach to patients (p.135).

However, a close reading of the article also reveals that Engel's version of a more holistic approach did not include proper consideration of socio-economic factors such as poverty, poor housing, or inadequate access to healthcare. Such factors impact on how people experience ill health or impairment, as well of course as influencing their incidence. In the extract from the article quoted above, it is notable that the factor Engel identifies as important in determining whether a patient experienced a condition as merely a 'problem of living' "has basically to do with whether or not he accepts the sick role and seeks entry into the health care system". The emphasis seems to be on individual psychology with no recognition of how, for example, material resources can mitigate or worsen the impact of illness or impairment. In an article published three years later, which attempted a "clinical application of the biopsychosocial model" (Engel, 1980), the reluctance of a man to seek medical help, despite his symptoms of acute myocardial infarction, is explained entirely in terms of individual psychology and the contextual relationships. There is no consideration of the possibility that he may have been concerned that acknowledgement of his condition would lead, for example, to unemployment and poverty for his family, and/or the high costs commonly incurred in the US healthcare system. This emphasis instead on individual psychology and the roles that people adopt, accompanied by a failure to fully acknowledge the impact of socio-economic factors on people's experiences of, and responses to, ill health and impairment is replicated within all the documents with which this chapter is concerned.

5.3 The application of the biopsychosocial model to low-back pain

In 1987, Gordon Waddell, a Glasgow orthopedic surgeon, published an article which drew on Engel's proposals for a new biopsychosocial model to, in this instance, explain and recommend responses to low-back pain. He thought that the BPS was "very much a model of human illness rather than disease and may equally well apply to non-psychiatric illness" (Waddell, 1987, p.637). He

argued that "at some stage in their life, 80% of the human race will experience low-back pain"; that seeking treatment for such experiences was correlated with "the introduction of Western medicine"; and that "a total of 80-90% of attacks of low-back pain recover in about 6 weeks, irrespective of the administration or type of treatment" (*Ibid.*, p.632).

Waddell was writing at a time when there was increasing questioning of 'bedrest' as the standard treatment for low-back pain, and increasing evidence that some activity and exercise was beneficial, particularly because "prolonged rest leads to increased psychologic distress and depression, loss of the work habit, increased difficulty in starting rehabilitation, progressive loss of job opportunity, and decreasing probability of ever returning to work" (p. 640). He was also writing at a time when there was increasing recognition that many surgical interventions for low-back pain were ineffective and in fact could leave patients in more pain than before. He concluded that "Conventional medical treatment for low-back pain has failed and the role of medicine in the present epidemic must be critically examined" (p. 636).

In surveying the evidence Waddell distinguishes between low-back pain and 'disability' (by which he means loss of function), both of which he says are related to underlying disorder or impairment but the assessment of pain and incapacity (by both patient and doctor) is subjective and influenced not only by "the objective physical abnormality but also by the patient's attitudes and beliefs, psychologic distress and illness behaviour" (p.635). He goes on to question the 'objective physical abnormality' of chronic pain when he contrasts it with acute pain:

> …acute pain, acute disability, and acute illness behaviour are generally proportionate to the physical findings. Pharmacologic, physical and even surgical treatments directed to the underlying physical disorder are generally highly effective in relieving acute pain. Chronic pain, chronic disability and chronic illness behaviour, in contrast, become increasingly dissociated from their original physical basis, and there may, indeed, be little objective evidence of any remaining nociceptive stimulus. Instead, chronic pain and disability become increasingly associated with emotional distress, depression, failed treatment and the adoption of a sick role.

Chronic pain progressively becomes a self-sustaining condition that is resistant to traditional medical management.

(Waddell, 1987, p. 636)

This approach influences his assessment that "simple low-back pain is not a disease" (p. 641). He argues that, in contrast to a condition such as disc prolapse, which is discernible and treatable, back pain which is not alleviated by the treatments available and which therefore becomes 'chronic' is to be explained more in terms of "illness behaviour". The physician therefore needs to distinguish "the symptoms and signs of psychologic distress and illness behaviours from those of physical disease" (p. 641).

He concludes:

It is unlikely that there will ever be a magic cure for all low-back pain, so the physician's role as healer must be accompanied by his or her more ancient role as counsellor, helping patients to cope with their problems. The patient's role must correspondingly change from passive recipient of treatment to a more active sharing of responsibility for his or her own progress. The main theme of management must change from rest to rehabilitation and restoration of function.

(*Ibid.,* p.641)

As we shall see, Waddell went on to be closely involved in the development of the application of the BPS to the assessment for out-of-work disability benefits, and his thinking about the role and status of 'illness behaviours' was developed further. Like Engel, he recommended "the need to consider the physical, psychologic and social aspects of illness" (p.640) but again like Engel his consideration of 'social aspects' was confined to identifying the part that both physicians and patients play in the creation of the "sick role" and "low back disability" (p. 641).

5.4 The argument for 'objective' assessment of 'subjective symptoms'

Waddell had identified that low back pain was an increasingly common condition amongst people claiming sickness and incapacity benefits in both the

United Kingdom and the United States (Waddell, 1987, pp. 633-34) but this was just one of a number of chronic conditions involved in the rise in sickness and incapacity benefit claims on both sides of the Atlantic. When the Department for Social Security considered reforming invalidity benefits in the early 1990s, Peter Lilly, Secretary of State, drew on advice from the American private income protection and disability insurance industry, whose profitability was being undermined by similar patterns of long-term disability claims as were experienced within the UK benefits system (Rutherford, 2007). John LoCascio, Vice President of Unum (which later become Unum Provident) advised on the design of the All Work Test and in the recruitment and training of doctors (with a job title of Disability Medical Analysts) to advise the non-medical adjudication officers.

As Chapter 3 described, the All Work Test introduced in 1995, when Incapacity Benefit replaced Invalidity Benefit, meant that eligibility was determined by the ability to do any work and not just the person's 'usual occupation'. Applicants' own doctors were removed from the assessment process although they could be called upon to give supporting evidence if required.

The thinking behind this change in the approach to eligibility is illustrated by an article co-authored by John LoCascio and Mansell Aylward (then Principal Medical Advisor at the DSS) in the Journal of Psychosomatic Research in 1995. They argued that medical practitioners were too ready to take their patients' 'subjective' symptoms at face value and that this was largely responsible for the increase in the numbers of people deemed eligible for long-term out-of-work disability benefits:

> We believe that the increase in the number of people receiving Invalidity Benefit (IVB) is due to a major cultural shift in medical practice. 'Subjective' impairments….which in the past have been considered an insufficient basis for chronic, total incapacity, are now increasingly cited as the sole manifestation of a variety of conditions which feature prominently among claims for Incapacity Benefits and Long-term Disability.

> (Aylward and LoCascio, 1995, pp. 757-758.)

They went on to say that there was an increasing number of people claiming long-term benefits whose symptoms could not be explained by 'objective' impairment or disorder, who displayed "disproportionate symptoms", and where the "expected degree of impairment would not prevent gainful employment but the reported impairment does" (*Ibid.,*p. 761).

Their approach is not the holistic one which some have argued was originally put forward by the biopsychosocial approach to illness (Shakespeare et al, p.22). Instead, there is greater emphasis placed on psychiatric conditions in the context of 'subjective' symptoms:

> We believe that formal psychiatric evaluation should always be considered for the patient with a chronically disabling condition and especially so in cases where 'subjective' issues dominate the picture of incapacity.
>
> (Aylward and LoCascio, p. 760)

This psychiatric evaluation is required, they say, because: primary care physicians sometimes miss acute psychiatric illnesses which are treatable; some chronic 'subjective' symptoms "require the appropriate assessment of psychiatric aetiology and morbidity (e.g. Chronic Fatigue Syndrome)"; and even if there is no "overt psychopathology, disproportionate impairment requires the thorough evaluation" of conditions such as "personality disorders" (p.760). They conclude that medical practitioners should play no role in determining eligibility for long-term disability benefits but that "clinicians, including psychiatrists and psychologists can provide useful information about individual patients and can also clarify the underlying concepts about psychiatric disorder and psychological contributions to disability" (p. 764).

In this version of the biopsychosocial model therefore the approach is quite clearly not one of recognising how social *and* psychological factors can influence the experience of a bio-medical condition. Instead the argument is that many chronic conditions have no physical basis but are the result of "psychopathology".

5.5 Malingering and Deception

Despite the change in assessment of eligibility brought in by the All Work Test, the numbers of people deemed eligible for Incapacity Benefit did not fall and, as discussed in chapter 3, in 1998 the Labour government introduced yet another 'more objective' assessment (the Personal Capacity Assessment), this time intending to focus on what a person *could* do rather than what they couldn't. There remained concerns, however, that neither the benefit system nor the programmes intended to help people into work, were making much of an impact on the numbers claiming long-term benefits and, in November 2001, the Department for Work and Pensions (DWP) funded a conference which brought together academics and medical practitioners from a range of disciplines, lawyers, civil servants and representatives of private insurance companies. Amongst the attendees was Malcolm Wicks, a Minister of State for Work and Pensions, and Mansell Aylward, who was now the Chief Medical Officer for the DWP, as well as John LoCasio from Unum insurance. The title of the Conference was "Malingering and Illness Deception" and, as the resulting publication set out, it was to consider the proposition that:

> There is a need for a paradigm shift away from the implicit determinism of the biomedical model and a move towards the proposition that human beings, in most everyday situations (including many aspects of their illness) possess a sense of control and influence over their actions (as opposed to behaviour); that is, they can choose between different courses of action.

> (Halligan et al, 2003, p.5)

We have seen that Waddell's emphasis in his 1987 article about low-back pain was on the role that clinical practitioners played in the creation of the 'sick role' amongst people whose level of symptoms and limitations could not, apparently, be medically explained, as well as on the change in medical consensus about the best treatment for most low-back pain, and the need for the patient to take an active role in their recovery. Aylward and LoCascio's 1995 article, in describing the thinking behind changes in the assessment of eligibility for long-term benefits in both the state and private sector, emphasised psychopathology

in explaining 'disproportionate' and 'subjective' symptoms. Now, the contributors to the 2001 Conference placed significant emphasis on the individual's 'free will' and 'personal responsibility', and also on the contention that 'illness deception' was more common than widely assumed to be. Indeed, the publication resulting from the Conference starts with two quotes:

'Deceiving others is an essential part of everyday social interaction' Aldert Vrij (2001)

'You must believe in free will: there is no choice' Isaac Singer

(Halligan et al, 2003, p. 3)

The conference focused on the extent to which illness and impairment (and some types of illness or impairment in particular) is not to be explained medically but by 'illness deception' or the 'sick role', with an emphasis placed on the financial incentive to claim incapacity, created by social security systems and private insurance.

Over the past 30 years, more generous benefits have become more widely available. It seems unlikely that medical factors alone can adequately explain the large uptake in work-related incapacity benefits in most countries since the 1970s, despite improvements on most objective measures of health.

(Halligan, Bass and Oakley, 2003, p.3)

In their introduction to the Conference papers, Halligan et al argue that while "the biomedical model largely ignores the fundamental notions of responsibility, free will, and the patient's capacity to choose" so too does the biopsychosocial model: "Despite philosophical differences, most medical and biopsychosocial models share a common assumption: namely, that the person seeking help from a doctor is largely the victim of an endogenous biopsychosocial vulnerability or physical pathology which is beyond his/her control" (p.11). We are all capable of "exaggerating or feigning illness" they say and to deny the possibility of conscious intention to deceive is to deny "what is essential to our humanity—namely, our free will".

They conclude that it is inappropriate for medical practitioners to play a central role in determining eligibility for out-of-work disability benefits. Medicine, they say, has accepted a "growing number of symptom-based illnesses and a more tolerant attitude towards illness deception. By blurring this distinction between willful deception and medical disorder, illness behaviours could be explained in terms of an ever-expanding list of psychopathologies and the growing recognition of psychosocial disorders". Emphasising that there has been a "three-fold increase in claims to incapacity benefits since 1970 in the United Kingdom and other countries despite improvements in most other indices of health", they conclude "by neglecting non-medical explanations for illness behaviours modern medicine runs the risk of underestimating the capacity of individuals to influence and control their actions as they do successfully in many other non-medical areas of their life" (p. 23).

Aylward's contribution to the Conference concerned a discussion of the role and intellectual framework of Disability Assessment Medicine. This, he said, was a recent and growing 'discipline' whose function, he said, is to "assess impartially how a person is affected by disease or disability and to relate this to policy, legislative requirements, insurance products or specific issues raised by decision makers who determine eligibility for cash and other benefits under these various schemes", and the growth of which has "been driven by dramatic increases in sickness and incapacity for work associated with musculoskeletal disorders, mental health problems, and 'subjective health complaints' in Britain and other more developed democracies" (Aylward, 2003, p. 287).

While acknowledging the importance of the biopsychosocial model, Aylward also identifies "an understandable reluctance by many protagonists of the biopsychosocial philosophy openly to debate and critically explore the possibility that some illness behaviours may be driven by choice and conscious intent" (Ibid., p. 298). This reluctance means that the model has a tendency to adopting "a creeping medicalization of ill-defined syndromes of questionable aetiology by cultivating a proliferation of descriptive psychiatric diagnoses of uncertain scientific validity" which "perpetuates a deterministic culture which very substantially diminishes an individual's capacity to make value-driven choices" (p.298).

Aylward argued that biopsychosocial models provide 'disability assessment medicine' with a useful conceptual framework but that their "apparent failure to acknowledge that illness behaviours may also be driven by the subject's choice and intent is a formidable barrier to the adoption of a coherent and robust stance by the practitioner of disability assessment medicine" (p. 296). He concluded that there is a need to clarify "ambiguities about the relative contributions to the provocation and perpetuation of illness behaviours by volition and intent on the one hand and biopsychosocial influences on the other" and that disability assessment medicine "offers the intellectual framework within which fruitful debate and dedicated research should be encouraged to flourish" (p. 298).

Overall, the conclusion of key people involved in the Conference seemed to be that the biopsychosocial model was in danger of placing too much emphasis on psychological factors over which the individual has little control and it is therefore at risk of taking a too deterministic and over-medicalised approach when applied to assessing eligibility for out-of-work disability benefits. Instead, the disability assessment process must also acknowledge that individuals have free will and may be adopting 'illness behaviours' of their own volition.

5.6 "A theoretical and conceptual framework for incapacity benefits"

As part of the Labour government's continuing development of their welfare reform agenda, the DWP commissioned Waddell and Aylward to write a report, published in 2005, which set out to "return to first principles and revisit the questions: What do we want the welfare system to achieve? Are we achieving it? How do we need to modify policy and practice to better achieve what we want?" (Waddell and Aylward, 2005, p.11). In particular, they aimed to "develop a theoretical and conceptual framework for incapacity benefits for people of working age" (p.7). Titled "The Scientific and Conceptual Basis of Incapacity Benefits", the report claimed to "provide a scientific evidence-base for IB reform to meet today's challenges and needs" (Ibid).

Their report divided those on Incapacity Benefit into two main groups: those with "severe and permanent impairments"; and those with "less severe 'common health problems': mild/moderate mental health, musculoskeletal and

cardio-respiratory conditions" (p.8). This latter group was identified by Gordon Waddell in a previous publication as conditions which "consist primarily of symptoms with limited evidence of objective disease or impairment" where "the obstacles to recovery are often predominantly psychosocial in nature rather than the severity of pathology or impairment" (Waddell and Burton, 2004, p.7)

They take rather a biomedical approach to the first group, including within it people with conditions such as tetraplegia and paraplegia and people who are blind, without seeming to recognise that removal of attitudinal and environmental barriers, and changes in working practices, can enable people with such impairments to be engaged in paid employment. The key defining characteristic which seems to justify putting people with such impairments in the same group as those who are in "a persistent vegetative state" (p.207) seems to be that they have a condition which can be objectively determined (the full this of these "severe and permanent impairments" is shown in Appendix 2 of their report). So, for this group, the diagnosis is the qualifying criteria, unlike, as we shall see, the approach taken to the second group of IB claimants identified.

The report is primarily concerned with this second group - those with 'common health problems' who are said to make up about two-thirds of claimants. They contend that "the less severe and more subjective the health condition, the more important the role of personal factors (motivation and effort, attitudes and beliefs, behaviour, functioning and participation)" (Waddell and Aylward, 2005, p.8). They then qualify this statement by saying "That does not mean these people are all 'malingerers'" but then go on to say, "it is appropriate to question whether all IB recipients are equally incapacitated for work and to suggest that claimants must bear some responsibility for managing their own health, rehabilitation and return to work" (Ibid).

Throughout the report the authors make the assumption that it is these personal factors which are most important in determining whether someone who has a 'common health problem' is working or not. They often make a passing reference to social factors but each time they avoid a full recognition of the possible barriers stemming from social context and return instead to the

issue of individuals' 'attitudes' and 'motivation'. The following paragraph can be analysed as just one of many examples (p.9):

"There is a conceptual difference between those who 'can't work' because of their physical or mental condition and those who 'can't get a job' because of their physical or mental condition, but in practice there may be much overlap". This sentence hints at the possible relevance of attitudinal and environmental barriers, over which the individual has little or no control, which can shut people out from employment opportunities.

"Personal factors, the social context and the impact of the social security system itself on human behaviour ('moral hazard') may be excluded from legislative and administrative definitions, but their importance cannot be denied". The social context' is listed but no further details provided to fully recognise its importance - either here or anywhere else in the report - other than the financial incentive said to be created by the availability of out-of-work benefits.

*"*The limitation of any assessment is that it ultimately provides information about performance: it may never be an objective measure of what the claimant is *able* to do or *should be able* to do." Although the aim is to develop an 'objective' assessment of what someone is able to do, this is a recognition of the limits to 'objectivity'.

*"*As an over-simplification, capacity may be limited by physiology, but performance is limited by psychology: what the claimant does or does not do will always depend on effort and motivation." There is no recognition that disabling barriers - the physical or working environment, lack of equipment etc. - may limit performance. Instead, it's only 'effort and motivation' - a very limited type of "psychology" factor - which are considered relevant.

"The age-old dilemma sometimes remains of how to distinguish those who can't work from those who won't." The assessor has to consider whether someone is 'motivated' to make an 'effort'. So, we are now back to the issue of "malingering" and "illness deception": interestingly, the

reference the authors give for this last sentence is Henry Mayhew who, writing in 1861, divided the London poor into those who will work, those who can't work and those who won't work.

They then go on to contend that "many IB recipients" experience "incapacity without disease or impairment" and that "one of the main social security problems today is the number of people whose incapacity is based on feeling ill (and therefore limited in their activities), claiming the sick role, legitimised by sick certification, often in the absence of commensurate disease or impairment" (p.30).

Throughout the report there is much emphasis on attitudes and culture: the primary 'gateway' to sickness they say is "effectively a 'social' gateway":

> The initial decision to stop work is commonly made by the individual, with or without the advice or agreement of health professional(s). This decision is influenced by many factors including but not limited to the health condition: the key factors appear to be the individual's perception of his or her symptoms, the nature of work demands and the psychosocial and cultural context.
>
> (p.105)

This perspective places prime responsibility on the individual for the route to unemployment and appears to question the legitimacy of their decision. Similarly, they argue that what was then the 'gateway' to out-of-work benefits placed too much emphasis on "claimants' self-report of subjective symptoms and limitations" (p.173) and the solution lies in a more 'objective' assessment of incapacity than is achieved by the Personal Capacity Assessment.

Throughout the report, Waddell and Aylward are arguing that social attitudes about health and work have to change. They believe that, in order to achieve the aims of reducing the numbers on long-term benefits and increasing the employment rate amongst disabled people, it will be necessary to change how disabled people see themselves and also how they are treated by the NHS and by the social security system. "The ultimate aim" they say:

is a fundamental transformation in the way sick and disabled people see themselves and in the way they are treated by the health care and social security systems (p.121).

In order to do this, it will be necessary to change not only the benefits structure but also the way individuals - health professionals, employers and disabled people - think about both 'incapacity' and work (pp. 121-122) and, they argue, changes in the way health professionals and patients have responded to back pain is an example of how such a transformation can be made. This, they argue, has led to a dramatic fall in the number of new IB claims for back pain (p.124).

Like politicians at the time, Waddell and Aylward were particularly concerned that "mental and behavioural disorders now account for 42% of the IB caseload". They believed that "the vast majority of these recipients have mild/moderate mental health problems" (p.134) and that the failure to "reduce inflow" reflects a "failure of control mechanisms". There has been too much reliance, they say, on the self-reporting of symptoms and incapacity. Criticising the changes that had recently been made in the definition of 'disabled person' in the Disability Discrimination Act (which had made it easier for people with mental health conditions to claim 'protected' status), they contend that medical diagnosis is more valid evidence than the person's own experience of their condition:

Given that impairment is, by definition, objective, it is not clear how it can be based solely on subjective experience and self-report without some form of medical diagnosis.

(p.135)

However, they also argue that diagnosis does not determine incapacity: "diagnosis may establish possible entitlement, but does not assess the level of disability - impairment is a necessary but insufficient basis for incapacity" (p.135). They therefore recommend an "extensive programme of research and development" in order to develop not just the mental health functional areas and descriptors but also the thresholds at which "the condition starts to impact

on capacity for work and at which a person cannot reasonably be expected to work" (p.136).

Neither this 'extensive' programme, nor the improvements in access to clinical and occupational health services which Waddell and Aylward also recommend as crucial to the reform of Incapacity Benefit, materialised in the way they intended. Instead, the focus of replacing Incapacity Benefit with Employment and Support Allowance was on reforming the mechanism by which people's incapacity for work was assessed, downgrading the relevance of diagnosis and professional expertise and with the emphasis on replacing 'subjective', 'self-reporting' with an 'objective' assessment in which observation plays a key role (as discussed below).

5.7 "Free will, conscious choice"

In their 2010 publication which further developed their approach, Waddell and Aylward return to the issue of what determines performance, asserting that "performance is limited by how the person thinks and feels about their health condition'. (Waddell and Aylward, 2010, p. 20). They criticise the biopsychosocial model for tending to place too much stress on psychological factors and not enough recognition of individuals' free will and personal choice:

> The biopsychosocial model has sometimes been taken to imply that patients are the powerless victims of psychosocial forces beyond their control. Despite acknowledging mental events, its emphasis on physiological and psychological mechanisms remains deterministic. This fails to allow for free will, conscious choice.

> (Ibid., p. 27)

They briefly discuss the social model of disability but dismiss it as a "political model" and also argue that it has more relevance to those with 'severe' impairments - and even then, they say, its relevance is limited by the need to include individual attitude and motivation (p.14). As a result, the barriers to getting and keeping employment associated with negative attitudes, inaccessible physical and communication environments, and disabling working practices are never seriously considered. The only social factors that Waddell

and Aylward seem to consider relevant to explaining levels of out-of-work disability benefit claims are those which supposedly encourage people to claim such benefits. Thus, they argue that people's 'subjective' beliefs that they are ill "are often reinforced by medical advice", "by employers who will not permit return to work until symptoms are 'cured'" and "by the benefits system" (*Ibid*, p.5).

Echoing their earlier report, this 2010 publication focusses on 'common health conditions', emphasising that:

> About two-thirds of long-term sickness absence, incapacity benefits and ill-health retirement are now due to less severe health conditions, the most common of which are mild/moderate mental health, musculoskeletal and cardiorespiratory conditions.
>
> (p.6)

In drawing a distinction between "people with severe medical conditions and permanent impairment" for whom welfare systems "were originally designed" (p.6) and people with these common health conditions, Waddell and Aylward again return to the need to question 'subjective' symptoms, particularly amongst people with 'mild/moderate mental health conditions'.

> there is a qualitative difference as well as a difference in degree between the two ends of the spectrum, for example between schizophrenia and a subjective complaint of 'stress'. There is a conceptual distinction between subjective symptoms and objective disease, which is fundamental to healthcare and social support. Common health problems are very different from the severe medical conditions and permanent impairments for which sickness and disability benefits were originally designed.
>
> (p. 8)

Although Waddell and Aylward, in this 2010 publication, do again stress that there is a very low rate of fraudulent claims for out-of-work disability benefits, their emphasis is on how the 'subjective descriptions' by people with 'common health problems' should not be taken as relevant for the 'objective' assessment

of capacity to work. They emphasise that the need for 'objective assessment' is even greater because so many people on IB report mental health conditions as a primary or secondary cause for incapacity (Waddell and Aylward, 2010, p.7). Within their model, 'impairment' - by which they mean "significant, demonstrable, deviation or loss of body structure or function" (*Ibid.,* p.3) - gives the "most objective measure of a health condition" (p.5). However, they say:

> Because of their nature, there is difficulty applying the concept of impairment to mental health problems……*mental impairment* should refer specifically and solely to abnormalities of mental function that can be demonstrated, assessed, evaluated and measured by an objective observer on mental state examination: e.g. cognitive function, thought disorder, impaired judgement, disturbed mood and behaviours. It is particularly important to distinguish such observed impairments from individuals' subjective descriptions of their symptoms and limitations.

> (Waddell and Aylward, 2010, p.4)

As we shall see from the experiences of people going through the WCA, implementation of this thinking means that the observation of a claimant's behaviour during the assessment is taken as more relevant than the person's own description of how their day to day functioning is limited by their mental health condition. The 'theoretical and conceptual' framework which underpins the WCA means that people's self-reporting of their symptoms and capacities is contentious, and if someone has a 'common health problem' the main determinant of their experiences is assumed to be their own 'free will':

> Very few have a severe mental illness or disorder that absolves them from responsibility. For most people with common health problems, decisions about being (un)fit for work, taking sickness absence or claiming benefits are conscious and rational decisions, free choices with full awareness and intent, for which they must take responsibility.

> (p.22)

5.8 The Work Capability Assessment

Following Waddell and Aylward's 2005 report, as we have seen in Chapter 3, the Labour government commissioned David Freud (later to become Minister for Welfare Reform under the subsequent Coalition and Conservative governments) to carry out a "wide-ranging review of our welfare to work strategy". This review was intended to address, according to the then Secretary of State for Work and Pensions, John Hutton (2006), "How we can tackle the 'can work, won't work' culture" - a statement which echoed the words of Waddell and Aylward in the paragraph from their report analysed above.

The WCA replaced the Personal Capacity Assessment when Employment and Support Allowance was introduced in 2008. It aimed to 'objectively assess' function, with a significant reliance on observation, treating diagnosis as more or less irrelevant (except for those with 'severe and permanent impairments'), and regarding claimant's self-reporting of symptoms and function as contentious and irrelevant for the purposes of assessing eligibility. Although the WCA itself asks a series of questions to claimants about what they are able to do, the 'theoretical and conceptual framework' assumes that the person's opinion is suspect and must be judged by the assessor, in conjunction with the computer programme which guides them through the assessment (see below).

In placing such a causal emphasis on individuals' motivation, attitude and behaviour, the framework on which the WCA is based assumes that factors such as availability of employment, the nature of such employment, discriminatory attitudes and inaccessible physical and communication environments are not key determinants of employment opportunities. This denial of the validity of the social model approach, with its emphasis on disabling barriers, is primarily applied to those experiencing 'common health problems', and thus they are being defined as 'not really disabled'. As Shakespeare et al, argue:

> By saying that the social model is not relevant to this population, and by differentiating 'common conditions' from 'severe conditions', advocates of the Waddell-Aylward BPS are advancing a distinction between 'real'

incapacity benefit claimants, with long-term and incurable health
conditions, and 'fake' benefit claimants, with short-term illness.

(Shakespeare et al, 2017, p.33.)

It is government policy priorities about reducing the numbers of people on long-term out-of-work disability benefits which are driving this agenda. As Chapter 3 explained, the replacement of Incapacity Benefit with Employment and Support Allowance, and the Personal Capability Assessment with the Work Capability Assessment, was intended to reduce the numbers claiming out-of-work disability benefits by 1 million (Department for Work and Pensions, 2006, p.3). In particular, the policy agenda associated with the adoption of the WCA assumed that it would dramatically reduce the numbers of people qualifying for long-term out-of-work sickness/disability benefit (those in the Support Group of the ESA). The Labour government's 2008 consultation proposed that "For the vast majority, ESA will be a temporary benefit, supporting people until they recover from their health problem or are able to adapt to their new circumstances." (Department for Work and Pensions, 2008a, p.15), and the resulting White Paper confirmed that ESA was expected to be a "temporary benefit for the majority, with most claimants expected to move back into work within two years" (Department for Work and Pensions, 2008b, p.88); and 90 per cent were expected to be placed in the Work Related Activity Group (*Ibid.,* p.86). These policy aims have implications for the way the WCA was and is being implemented and experienced by those being assessed, as examined in Chapter 7.

An important aspect of the WCA is the way in which a computer system is used to try and ensure 'objectivity' and consistency in the assessment. This had in fact started under the previous assessment process for Incapacity Benefit. In 1998, the DSS Medical Service was contracted out to a private company, SchlumbergerSema. They introduced a new computer system called LiMA which was designed to guide assessors through the Personal Capability Assessment (the successor to the All Work Test and the fore-runner of the WCA), increase the standardisation of such assessments and produce electronic versions of the form IB85 which at that time was used by DWP

decision-makers to determine whether someone was eligible for Incapacity Benefit. SchlumbergerSema was taken over by Atos Origin, an international IT company who was then contracted to provide the Medical Service (Rutherford, 2007, p.42). Atos was eventually replaced by Maximus in March 2015 when Atos bought themselves out of the contract. LiMA continues to be used for the WCA although the software is updated from time to time.

Over the same period, the role of medically qualified doctors in the assessment process has diminished. When the assessment of incapacity for work was first removed from GPs it was carried out by doctors employed by the Medical Service. Over the years the role has been extended to nurses and physiotherapists and a generic job title of Health Care Professional (HCP) created. This is the type of role referred to by Mansell Aylward as "Disability Assessment Medicine" (see above) where the emphasis is placed on 'objectively' determining function. Job adverts for HCPs explain that "These assessments are designed to develop understanding of the specific impact an individual's long-term illness or disability has on their ability to work…..The functional analysis you carry out will focus not on a person's condition, but rather on the effects the condition has on that person" (Maximus, July 2017).

The training programme devised by DWP and used by Maximus suggests that a new role of 'Disability Analyst' is created by applying the 14 day programme on top of the professional qualification that HCPs already have (Medical Service, 2014). The intention is that this training programme enables the HCP - regardless of their specific clinical training - to have sufficient expertise to assess the functional capabilities of the whole range of impairments and illnesses that claimants may have. The WCA follows the downgrading of diagnosis recommended by Waddell and Aylward in their version of the biopsychosocial model. As the Training Handbook for HCPs says, "For the disability analyst, a precise diagnosis is of secondary importance. The primary function is to make an assessment of how a person's day to day life is affected by disability, and to relate this to the legislative requirements" (Centre for Health and Disability Assessments, 2018, p. 19). While it could be argued that this downgrading of the importance of diagnosis is a welcome retreat from an individual medical model approach, in practice it can mean that assessors are

very unfamiliar with the impact of particular impairments or illnesses and helps to create a conflict between their assessment and the claimant's lived experience, as will become apparent in Chapters 6 and 7.

In terms of my own experience of the WCA, when I asked the person doing one of the assessments I had what expertise they had regarding my impairment the only reply they could give was that they were a "disability analyst". When I asked what that meant they could not explain what that was other than that they "analyse disability". This obviously did not inspire much hope or confidence that they would have an understanding and knowledge of my problems and how they impacted on my ability to work.

In fact, it is clear that the 'descriptors' used to assess function do not relate to actual ability to get and hold down paid employment. Instead, they relate to daily living activities which bear little relationship to the reality of functioning within a workplace. The LiMA programme, which is accompanied by an 11,000 word training book, tells HCPs what to assess, providing a series of drop down menus, and suggesting 'logical' outcomes (in terms of points awarded) of the options selected, although the assessor can over-ride these outcomes (in which case they have to justify this). The programme has a section on 'Observed Behaviour', which requires the assessor to select whether ability or inability in observed behaviour is consistent or inconsistent with the "history, examination and medical knowledge of the condition". However, the programme will itself suggest whether the behaviour is consistent or inconsistent although again the assessor can over-ride this (Medical Services, 2011, p.41-42).

When the WCA started to be rolled out, the level of criticism and protest aimed at the Department for Work and Pensions and at Atos was unprecedented. Disabled People Against the Cuts in England and Wales, Black Triangle in Scotland, as well as local disabled people's organisations, organised many protests outside the buildings where assessments were carried out. A summary of such activities was published in Inclusion London's report *From Cuts to Resistance* (2015). DWP itself was dissatisfied with Atos' quality of written reports sent to the DWP Decision Maker and, from 2013, sought quality improvement (House of Commons Library, 2014). Atos paid to extricate itself

early from the contract to carry out Work Capability Assessments, partly because of the abuse its staff experienced but mainly because of the damage to its reputation. It was reported they were advised by a public relations firm that it had "extremely high brand recognition for all the wrong reasons" and the company's "shareholders and stakeholders" were very concerned about "both the reputational and profitability issues" they faced (Gentleman, 2015).

When Maximus took over the contract - charging DWP an increase from £115 to £190 in the cost per assessment (House of Commons Committee of Public Accounts, 2016, p. 6) - the company was aware of the widespread criticism of the way ESA claimants experienced WCAs carried out by Atos and addressed this in a Frequently Asked Questions page on their website (Maximus, n.d):

> Are fit-to-work assessments done fairly for disabled people?
>
> MAXIMUS has hired a leading benefits campaigner (Sue Marsh) to represent benefits claimants and has pledged to significantly improve people's experience of an assessment.
>
> With MAXIMUS, all those involved in carrying out fit-to-work assessments are given Disability, Equality and Awareness Training, provided by Disability Rights UK. The aim is for assessors to improve their understanding of the practicalities of living with an impairment or a long-term condition and the barriers disabled people face.
>
> On our website we also state that it is important that applicants can demonstrate empathy, respect and sensitivity in assessment delivery.

The appointment of Sue Marsh, a well-known blogger and campaigner on welfare reform, as Head of Customer Experience at Maximus was met with considerable criticism from some disability organisations and activists while others were willing to suspend judgement before seeing whether her role made any difference to claimants' experiences (Pring, 2015a). Protests were organised in 25 different parts of the country on the day that Maximus took over the contract (Pring, 2015b) but subsequent campaigning activity against the company does not seem to have continued at the same intensity as that waged against Atos. For example, Disabled People Against the Cuts' Week of Action

in the summer of 2017 included two protests against Atos - one relating to its sponsorship of the World Para Athletics in London, the other to its role of assessing people for Personal Independence Payments - but no protests against Maximus (Disabled People Against the Cuts, 2017).

Nevertheless, widespread criticisms - both within and outside Parliament - have remained of the WCA and, at the time of writing (late 2017), the House of Commons Select Committee on Work and Pensions is carrying out an inquiry into both Work Capability Assessments and assessments for Personal Independence Payments.

Conclusion

This chapter has examined six key documents which, taken together, illustrate how a model of illness and impairment which claimed to encourage holistic approaches to patients was developed into a model which treated people's own accounts of their experiences as contentious and which assumed that 'choice and intent' played a determining factor in how people experienced what were designated as 'common health conditions'.

The chapter has also highlighted how a 'theoretical and conceptual framework' for the assessment of eligibility for out-of-work disability benefits was developed in the context of government's stated aim of reducing the numbers claiming such benefits, and Chapters 2 and 3 have set the context of that aim. Ministers in the Labour government of 2005-2010 stated that their intention was to assist disabled people to achieve the employment that most of them wanted, emphasising that work is good for people's health. The Secretary of State, for example, when giving evidence to the Work and Pensions Select Committee in 2006 emphasised that reforms to incapacity benefit were a part of the government's strategy to increase the overall employment rate to 80 per cent and that the aim of reducing the numbers on Incapacity Benefit by 1 million was part of this (Select Committee on Work and Pensions, 2006, para 44). Organisations such as the Disability Rights Commission were also supportive of such an aim, telling the same Committee that it was important to move away from the "low expectations' often held about disabled people's capacity for employment (Ibid, para 88). Such intentions co-existed, however, with the

development of the approach, described in this chapter, to assessing capacity for employment which contended that about two-thirds of claimants had 'common health conditions' (primarily cardio-vascular, musculoskeletal and mental health conditions); and that for these groups, as quoted above, "decisions about being (un)fit for work, taking sickness absence or claiming benefits are conscious and rational decisions, free choices with full awareness and intent, for which they must take responsibility" (Waddell and Aylward, 2010, p.22).

This approach fails to consider the situation of the UK labour market and, as discussed in Chapter 2, the particular problems people with these 'common health conditions' may have in gaining and sustaining paid employment. As Chapters 6 and 7 will show, research participants were clearly confused and exasperated by the functional assessment failing to consider how someone's impairment/health condition would impact on them in a workplace setting. This suggests the concern is not that work is good for someone's health - as the focus is not to ensure someone finds employment - the main aim is to reduce claimant numbers to help bring down public spending and to expand the active reserve army of labour.

The next two chapters examine the consequences for those going through an assessment (the Work Capability Assessment) which, as we have seen, has been developed with the following assumptions: that the majority of people applying for out-of-work disability benefits have 'common health problems' which are often not the result of discernible disease or disorder; that capacity for employment is profoundly influenced by individuals' 'choice and intent'; and that therefore 'fitness to work' can only be determined by an 'objective' assessment of function, aided by a computer programme, with the individual's own account treated as contentious.

Chapter 6: Experiences of the Work Capability Assessment

Introduction

Chapter 5 has analysed the ideological development of an approach to out-of-work disability benefits which culminated in the Work Capability Assessment (WCA), while Chapter 3 comprised a critical analysis of the policy background. Although the Conservative government seems, at the time of writing (December 2017), to have pulled back from making proposals to replace the WCA, there has been much discussion within policy and political circles about the need to reform the assessment. If this is to happen, it will be very important that those developing an alternative assessment consider information about experiences of the WCA, rather than relying on a 'committee of experts'. It is, after all, disabled people who are the experts in how their impairments and/or experience of illness affects their capacity for paid employment.

The personal experiences of the WCA which are the subject of this chapter will therefore need to be an as, if not more, important part of any attempt to develop yet another validating device. These voices have been conspicuously absent and, as Chapter 4 explained, the 'literal' reading of the survey responses with which this chapter is concerned is one attempt to enable them to be heard. This chapter aims to provide an account of experiences of the WCA, recognising that, as Priestley (1998, p.85) argues, we can only properly understand "structural barriers and oppressive cultural representations" when our analysis is informed by disabled people's personal experiences. This chapter therefore gives a voice to experiences as defined by disabled people themselves. These experiences then provide the material for Chapter 7 which seeks to provide a more interpretative reading of the data in order to understand the nature of the relationship being played out between disabled people and the state.

 As was mentioned in Chapters 3 and 5, there has been widespread criticism of the WCA. Some of this criticism relates to the way it is carried out, for example high levels of successful appeals have prompted concerns about the quality of

assessments, with - as is discussed later in this chapter - even the Department for Work and Pensions being critical of the work of assessors employed by Atos. Others have also criticised it for, not just the way assessments are carried out, but what is being assessed. Baumberg Geiger, for example, argues that the descriptors used in the WCA's assessment of functional capacities are not based on evidence about what is required by jobs in the current labour market (Baumberg Geiger, 2017, p.34). Instead, the descriptors were devised by a 'committee of experts' who claimed that they represented the "activities and functional capability that a reasonable employer would expect of his workforce" (Ibid). At no point were they tested against what is required in the average workplace.

There have been consistent criticisms of the WCA since the time of its introduction. Five independent annual reviews have been carried out, in 2010 through to 2014, and a number of recommendations made, some of which have been acted upon. The last independent review commented, "the overall effect of these and numerous smaller changes to policy, legislation and process, is that the WCA being delivered today is significantly different from that designed in between 2006-2008" (Litchfield 2014, p. 18). However, the criticisms have remained remarkably consistent over the years and are reflected amongst the survey respondents, including those who received an assessment since 2014.

The fifth and last independent review received evidence of "an undue focus on physical conditions when mental health was the prime cause of incapacity" (*Ibid.,* p.57) and this was also apparent amongst respondents to this research's survey, but other difficulties, which the review highlighted in the case of applicants with mental ill health, were also expressed by people with physical and/or sensory impairments and chronic illness. These included concerns about whether the Health Care Professional (HCP) carrying out the face to face assessment had relevant qualifications and experience, and criticisms that HCPs did not listen properly to what was being said.

The WCA has two stages to the process: an ESA50 form which the applicant completes; and a face to face interview carried out by carried out by a 'health care professional' (HCP) employed by Maximus, the company contracted by DWP to carry out the assessments (following the withdrawal from the contract by Atos). The 330 respondents to this survey were asked to answer a total of 14 questions about their experiences of both stages of the assessment. The majority had received an assessment in the last four years. The online survey questions are provided in Appendix 1, a breakdown of responses in Appendix 2, and a breakdown of the demographics of respondents in Appendix 3. Just over half respondents were women and the largest age group was those between 40 and 64 (50 per cent) with 40 per cent being between the ages of 25 and 40. The survey did not ask for someone's primary impairment, rather it allowed people to identify any impairment/health condition which applied to them. Mental health conditions were the commonest impairment reported (72.8 percent) closely followed by physical impairment (55.7 per cent) and chronic illness (49.7 per cent).

6.1 "Humiliated" and "shamed"

Before examining in some detail respondents' views about the ESA50 form and the face to face interview, it is worth highlighting that respondents often mentioned, unprompted, how distressing the whole experience was. Some wrote about how they feel 'humiliated' by having to share very private details about themselves. Others felt "shamed" by being made to feel "useless" and "hopeless", and stigmatised - "why do they think I am a scrounger".

When faced with filling the ESA50 form, which for some was "Too distressing to fill in alone", a common reaction was to feel "degraded" and "humiliated" by having to focus on inabilities and illness. One woman experiencing chronic illness said she felt she had to explain "how useless I would be" at working: "The form did focus my mind on why I wasn't getting jobs, the insurmountable barriers to conventional work and my physical limitations. It wasn't pleasant realising these things". These experiences are in direct contrast to the rhetoric of focussing on "what someone can do, rather than what they cannot" that - since the introduction of the Personal Capacity Assessment in 1998 -

governments have repeatedly claimed disability assessments will address. It is, however, perhaps unsurprising that respondents experienced the process as focussing so much on what they were unable to do since, as we have seen from descriptions of the assessors' role described in Chapter 5, the intention of the WCA is to identify functional limitations.

The following comments give a flavour of how, and why, it could be a very distressing experience filling in the ESA50 form:

> *It takes a long time to fill and it's very distressing to go through every aspect of your condition and to see how unwell you are.*

> *I survive my daily life by thinking about what I can do on my good days, yet this critical, long and intense document focused on my worst day, a very depressing experience.*

One respondent said she felt she was lucky in that she had the support of "a knowledgeable healthcare worker friend" yet still found "the process of elaborating on every difficult and often humiliating detail of my life, exacerbated my depression." Someone who is on the autistic spectrum with learning disabilities/difficulties explained: "I'm autistic... struggle with anxiety & depression. Didn't know what was relevant, how to explain... took me two weeks to write... much shame and overwhelm." A mother, supporting her son with autism and learning disabilities/difficulties voiced her frustration at the continuing reassessments and how distressing they are: "I think for people like my son, where there is zero chance of him working, they should have an exemption from questioning. I have had to fill out his ESA form 3 times in 5 years. It is very distressing."

The second part of the Work Capability Assessment is a face to face interview. The fifth and last independent review of the WCA recognised that these interviews are "potentially stressful" (Litchfield, 2014, p.83) but the comments provided by respondents to this survey illustrate just how disturbing some found the experience. People with a range of impairments and health conditions

wrote of how distressing they found the interviews and how, especially for those with mental ill health, even waiting for the interview can be a source of stress: "I've just been called for one and it's affected my health badly. I've been quite suicidal, my depression has gotten worse and I am a lot more hopeless. It's in a week or so. If I get my ESA cut off I don't know how I will cope or how I will be able to keep going".

Not only can the interview feel like an invasion into the intimate and private details of people's lives but, as with the ESA50 form, it can be a "humiliating" and "shaming" experience to have to focus so intensely on incapacity. "It's embarrassing to have to admit to someone's face how badly you're failing at basic adult functioning." "It was an awful experience" wrote one man who experiences mental ill health and another said "The questioning is intimidating. …Your intimate, personal everyday life put under a microscope. Awful."

I was so evidently distressed, leaving the assessment, that the security guard pursued me down the road, concerned for my safety.

Questions were fired at me quite rapidly, not giving me enough time to recall the answers, and made me so mentally exhausted part way through that my mind just shut down, I felt numbed exhausted and distressed

When mental ill health takes the form of extreme anxiety and panic attacks, an interview with a stranger who asks intimate questions, the result of which can have significant financial implications, is unsurprisingly a very difficult experience: "I found it very traumatic. The assessment officer noticed that I was in distress and called a paramedic, who put me through an ECG ordeal before putting me in a taxi to my local doctor's surgery".

The entire process quite obviously caused many participants deep pain and anguish:

It was dehumanising, degrading, and immeasurably impacted my mental health

It's inhumane…I wrack my brain daily to see what I could possibly try to do some work and stop the torment of relying on benefits but I cannot find or think of anything where I would be well enough to work even on a very part time basis and/or from home - I'm not well enough and therefore however much they punish me, demean me & torture me mentally & cut my money I can't work so I will have to keep going and try to live on whatever I am given

It was a major contributing factor in my suicide attempt in 2011, and having to reapply in 2012 and 2016 has again harmed my mental health.

This was also echoed in the focus groups and interviews, with one participant sharing their experience of having been sectioned following the mental distress the assessment had caused them.

These experiences illustrate the reality behind the study carried out by Barr et al, who analysed data relating to numbers of reassessments for out-of-work disability benefits between 2010 and 2013, and levels of suicides, self-reported mental health problems and anti-depressant prescriptions. These reassessments were of people who would have been on Incapacity Benefit and who were called for a Work Capability Assessment to see if they qualified for Employment and Support Allowance. Barr et al controlled for factors associated with variations in these mental health measures, such as differences in economic trends and public expenditure within local authority areas between 2010 and 2013, as well as pre-existing trends. The authors found a correlation between numbers of reassessments and increases in suicides, reported mental health problems and prescriptions for antidepressants:

In those areas where more people had experienced reassessment there was a greater increase in suicides, self-reported mental health problems and antidepressant prescribing….The multivariable regression analysis indicates that these associations remained after adjusting for other baseline area characteristics, economic trends and long-term trends over time in our three mental health outcomes. The estimates from these models shown in table 1 indicate that for every 10 000 people reassessed

there were approximately an additional 6 suicides (95% CI 2 to 9), 2700 cases of reported mental health problems (95% CI 548 to 4840) and 7020 items of antidepressants prescribed (95% CI 3930 to 10 100).

It was also quite striking how many people mentioned being made to feel fraudulent in some way. With people mentioning that assessor were hostile and trying to "catch you out"/"check you weren't telling porkies". These experiences added to the feelings of distress and stigmatisation.

> *My WCA was one of the worst experiences I have had to go through in my life. I was made to feel like a fraud and a liar, making excuses for myself rather than someone suffering from an illness. I was very upset throughout my assessment and at no point did my assessor seem to care or really acknowledge this. I felt entirely unhuman.*

> *I was made to feel like scum. It feels like we are assumed to be guilty of fraud, and laziness.*

> *The report was angled towards 'discrediting' my oral account of my limitations.*

Such experiences show the reality of an assessment process underpinned by the theoretical framework described in Chapter 5. A framework which is grounded in the notion that certain impairments/health conditions are a matter of 'choice and intent' and that claimants experiences of their impairments/health conditions should be considered contentious.

This chapter will now go on to present respondents' experiences of the two different stages of the Work Capability Assessment, identifying some common themes which emerged from both the online survey respondents and those involved in the focus groups and the interviews.

6.2 Experiences of completing the ESA50 form

The ESA50 form is the first stage in a process the result of which will have significant implications for a person's income and whether they are subject to conditions which they may find difficult to comply with (see discussion about sanctions in Chapter 3). Analysis of the survey responses reveals four main

criticisms of the ESA50 and these are discussed below before moving onto to look at experiences of the face-to-face interview.

6.2.1 Questions did not enable claimants to explain how their impairment/health condition restricted their ability to work.

Most found it either difficult or very difficult although those with physical impairments were slightly more likely to find the form easy or very easy (10 per cent) than those with mental health conditions (7.5 per cent).

Figure 2: How easy did this form make it to explain how your health condition/impairment/disability affects your ability to work?

Very easy	1 (0.3%)
Fairly easy	30 (9.3%)
Fairly difficult	114 (35.2%)
Very difficult	172 (53.1%)
Not sure	7 (2.2%)
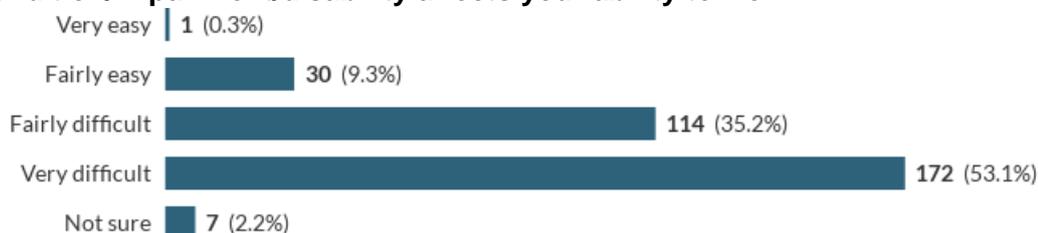
The first independent review of the Work Capability Assessment had recommended that the ESA50 form should include "a more personalised justification so the claimant can express the issues that they face in a short paragraph" (Harrington, 2010). Although the form does now include an introductory general question, this is about disability, illness or impairment and does not ask the applicant to explain how their capacity to work is affected. The detailed questions in the rest of the form about "ability to do things on a daily basis" bear little relationship to the practical realities of holding down employment. The form therefore makes it difficult for applicants to provide information relevant to "capability to work" (which is the name of the form) and this is reflected in comments made by survey respondents, many of whom confirmed that the questions bore very little relationship to the practical reality of being able to hold down a job.

As one woman, who was filling in the form on behalf of her chronically ill husband, commented: "The form is anything but straightforward, with questions that we feel have nothing to do with being able to hold down a real, everyday

job (I mean, what's with the 'being able to hold a 1/2 litre of milk' got to do with any real job, for heaven's sake, let alone being able to pick up a coin from a surface!)".

The fact that there wasn't sufficient space on the form to explain the nature of people's restrictions in the context of the practicalities of employment was of concern to many respondents. As one young woman with a mental health condition said, "The questions ask 'can you do [this]?' with a yes/no and it's usually not that simple. Also, it may be that you/I can do that precise task but not something very similar that may actually be more important to functioning. There's also nowhere to actually give an explanation of why you believe you can't work which would surely be helpful."

A number of people referred to how the "tiny boxes" on the form restricted how much they could say and, although there was an option of adding separate sheets, some said that this just added to the "overall complexity" or they were worried that additional sheets would get lost. A woman with both physical impairments and mental health difficulties added 6 A4 sheets in order to fully explain her situation and explained "Too many questions were not relevant and had no bearing on my health problems, had to write extra pages of info to make sure it was understood." A man with sensory impairment wrote of how he "ended up writing extra notes in the margins to explain my answers."

A lot of the advice from organisations such as the National Association of Welfare Rights Advisors and Citizens Advice Bureaux is aimed at enabling applicants to provide information that they know is relevant to the determination of someone's ability to work and this is necessary because the questions themselves do not make it clear what is being looked for. A young woman with physical impairments who also ended up writing lots of notes in the margins, expressed her frustration that "The questions were so vague and I felt that I was unable to explain how difficult my life is day to day and that yes, I could put an empty box on my lap and move it but seriously, WTF did that have to do with my ability to be able to work?!" A mother, filling in the form on behalf of her learning disabled daughter found it "quite difficult to explain how her condition affects her ability to work." And, as a woman experiencing chronic

illness said, "You also have to be "creative" (I mean think outside the box, not lie) when it comes to answering some questions because they seem to invite a vague answer, particularly from people who struggle with being articulate or with being about to see what a question is really asking (ie how that movement/task applies to the workplace)".

Even someone like one respondent with both physical and mental ill health, as well as sensory impairments, who was previously employed by the DWP, had difficulty answering the questions in a way which enabled him to provide information about his ability to work and found he still needed additional assistance:

> *I would consider that I have much more experience in these kind of forms than most, due to my previous employment by the DWP, as I have seen tens of thousands of similar forms. Even so I found the process extremely difficult, and after finishing filling it in, still had to add numerous amendments due to mistakes after having had to try to piece together text from different places. I am lucky in that I had a guide to filling out the form, and a proofreader with 30 years of DWP experience. Without a guide, personal experience and more experience to call upon, the chances of myself filling in the form to truly reflect my circumstances, and how my health conditions affect my ability to work would be slim. I suffer from mild cognitive impairment, which makes this type of activity difficult and distressing enough…*

6.2.2 Questions did not make it easy to explain impact of mental health conditions

Each of the five independent reviews of the Work Capability Assessment made recommendations to improve the process for people with mental health conditions yet the fifth and final review was still reporting problems, including inadequacies of the ESA50 form from the point of view of mental health (Litchfield, 2014). This was confirmed by survey respondents, a number of whom commented that the emphasis of the questions seemed to be on

physical ability. As a man with a mental health condition said, "The forms ask basic, easy questions that don't really relate to my mental health and the questions that do are difficult to understand. For example, I can physically communicate by speaking but because of mental health problems I often won't, but the form only allows me to choose this if it's because of a sensory problem."

None of the questions in Part Two of the ESA50, which concern 'mental, cognitive and intellectual capabilities' would elicit information about the impact of mental ill health unless the person was able to use the small boxes to write about the specific ways it affected them - and, as mentioned above, the questions do not relate to the practicalities of holding down a job. "The questions did not give me the opportunity to explain how my health condition affects my ability to work. The form was very biased towards physical impairment and mobility difficulties in my opinion." wrote one respondent while another found it difficult to explain his illnesses and felt that "the nature of the form meant more weight was given to physical restrictions than mental conditions". Tellingly, he said he "felt more assured explaining my epilepsy than my various mental health issues, despite them being more restrictive to my ability to work."

One woman, who has a diagnosis of autism and a mental health condition, asked "How can you quantify sudden waves of exhaustion, mind overloads where you just have to remove yourself from people or events, feelings of extreme fear and anxiety. Not being able to hear properly in a crowded room..just muffling voices overload etc, etc, etc….". Another wrote "I have depression and anxiety these forms are geared more towards physical impairments. Even the mental health categories focus on the physical limitations not mental ones", a criticism echoed by many other respondents: "It was hard to convey the debilitating effects of mental health problems on a form designed to assess physical ones."

People with both physical/sensory impairments and mental health conditions found that the questions assumed a single condition which made it difficult to convey how different conditions impacted on one another, for example: "I have

a mental illness, and am Profoundly Deaf but the questions seems designed to only apply to one disability either mental health issue or physical impairment, and both disabilities in myself impact the other, so it required a lot of "supplementary information" to answer the questions correctly."

Most questions on the form require a Yes/No/It varies answer and respondents with mental health conditions often said they had difficulty explaining the impact of their mental health. The difficulties experienced by people with fluctuating conditions of any kind are described below but people with mental health conditions raised particular issues around variations in ill health. These difficulties arose not only because the boxes to explain a 'It varies' answer are small but also because there are no questions which help to elicit information about the impact on capacity to work (as explained above). "It does not take into consideration that different days mean different things. Especially in terms of mental illness. It also barely scratched the surface of how mental illness affects a person" wrote someone who has both physical and mental health difficulties. As one man said, "It wasn't a good form to set out my health issues which are drug and mental health related. Also being in the process of working out my mental state I found it difficult to explain it in lots of detail as I don't fully understand it myself. Hence I have a problem." The inadequacy of the form can leave people feeling "confused and invalidated". As mentioned in Chapter 3, a High Court ruling in 2013 found that the WCA disadvantages people with mental health conditions (and those with learning disabilities and/or autism). Despite subsequent amendments to the process respondents to this survey indicate that the WCA continues to be unsuitable for measuring capacity for employment for people with mental health conditions.

6.2.3 People with fluctuating and/or multiple impairments found particular problems with the form

Although the questions and the design of the form have been amended to take account of some (though not all) recommendations made by both the independent reviews and by disability organisations, the form still posed particular difficulties for people with fluctuating conditions. For example, although it now includes an 'It varies' option, many respondents felt, as one

woman said, "The questions are not suited to capturing information about mental illness or about disabilities with fluctuating intensity". She went on to explain "one day I might be able to prepare a pot noodle alone, does that fit in with preparing a meal? If I can cook one day and then cannot get out of bed to eat for a week, the form allows no way to capture that without adding additional free hand sheets."

The most recent version of the ESA50 (February 2017) now has the following statement repeated for each section: "Only answer Yes to the following questions if you can do the activity safely, to an acceptable standard, as often as you need to, and within a reasonable length of time". This might help elicit relevant information from people with fluctuating conditions but the space to offer necessary explanations is quite small. Moreover, the questions themselves remain very limited and people found it difficult to get over the impact of a fluctuating condition on their capacity for work. One woman with chronic illness wrote that there was "nothing to explain the reality of living with a highly variable condition. It was very focused on a certain idea of work, reputable physical tasks etc that bear no relation to reality!". Another, who said she had a physical impairment, found that the questions did not enable her to "accurately describe my limitations. Day to day I am affected differently…the form is designed and only allows a static snapshot as opposed to a holistic picture of your life living with a disability".

In 2011, six organisations representing people with fluctuating conditions recommended that the government adopt a definition of 'work' based on 'real life' criteria such as that included in the Australian assessment system (MS Society et al, 2011). These criteria include the ability to "reliably perform their work on a sustainable basis without requiring excessive leave or absences". This recommendation was not adopted and the ESA50 form, as well as the face to face assessment, continue to create difficulties for people with fluctuating conditions. The limited focus on functional capacity, rather than giving people the opportunity to explain how their work capacity was limited in real life, created difficulties across a range of impairments.

One woman who, has a physical impairment, wrote of how "my condition varies from day to day. Filling it in, I was aware I needed to fill it in for the bad days, but it's difficult when you're constantly thinking 'They'll think I'm a fraud on a good day'". People with more than one condition also found it difficult to get across how they were impacted: "I have a combination of disabilities that are of a degenerative nature, the form does not account for that", wrote a woman with chronic illness as well as a mental health condition. "While some questions were clear enough" wrote another whose mental health condition fluctuates, "many felt too categorical about differentiating between states, took insufficient account of variable states over the long term (E.g. spending most of the year in severe depressive episodes but form may coincidentally arrive during a 'good' episode then focus on a short window around it), and others felt vague as to what was being enquired about given so many things could hypothetically fall under them."

The difficulties created by the limited nature of the questions asked on the ESA50 form were particularly apparent for respondents with ME, illustrated by one respondent's experience **"**Questions were framed specifically towards physical disability, but not physical and mental exhaustion, or adverse reactions/delayed symptoms from activity. I don't believe the questionnaire was geared in any way to sufferers of M.E/CFS/Fibromyalgia, depression or hypothyroidism, which are extremely debilitating. There was little opportunity to portray a realistic picture of living with these conditions and the difficulties experienced."

6.2.4 People often felt they needed additional knowledge and/or support to fill in the form and this was not always easy to get

A number of people commented that they felt special knowledge was required in order to fill in the form accurately and that they didn't always have this knowledge;

> *Often when filling in these forms they look for certain words. I have to ask*
> *for official help as they know the words that the powers that be look*

for…The forms are incredibly difficult to navigate. I always need help
when filling them in, via a local support team or social worker

As an autistic person, I have difficulty communicating about basic topics,
trying to explain how my condition affects me potentially requires a
psychology degree that I just don't have. Surely asking a health
professional how it affects me is more accurate.

It's daunting and unless you have expert advice or you are well informed
and have a flair for research, you are going to fail at describing your
condition accurately.

It's clear, when I face up to it, that depression and related issues have a
genuine impact on my ability to function generally and to get back to work,
but it's very hard to understand that myself, to describe it in terms that
make sense to someone else, and most importantly to fit that limited
understanding into the categories required by the form with some
awareness of how it's going to be judged. It's unfortunately the case that
the system isn't designed or run to identify those in need, but only those
with the stamina, support and good fortune to prove it with respect to an
arbitrary set of criteria.

Respondents who had some knowledge of the criteria against which they were
being assessed felt that they had an advantage when it came to filling in the
ESA50, for example one wrote: **"**Because I had read up on the law, I filled in
the form according to how my condition related to that criteria rather than
directly answering the questions and was put in the Support Group". Another
respondent expressed quite a common opinion, amongst both focus group and
survey respondents, that "It's all coded in very specific language, and things
have to be written in a very particular way if you're going to get the help that
you, so often, very desperately need. I am lucky in that I was aware of all of this
before I applied - but so many aren't…"

Some people felt that they had to put a lot of preparation into being able to
understand what was needed in order to fill in the questionnaire properly. One

woman, for example, had read up on "how to respond to the questions regarding my specific medical condition. i.e. describing how I am affected during an 'attack'…, rather than listing symptoms." and similarly, another "felt I needed to write a lot extra and get advice on what they were looking for."

Having access to support and advice to fill in the form was felt to be crucial by some respondents: "I had to ask for help from my local disability association" said a man who has both physical impairments and a mental health condition, and one woman with autism was amongst a number of people who mentioned finding advice and guidance online "If I hadn't received help from an online guide to fill it in I would have found it almost impossible. As it was I had to make use of the additional details bits a lot, ending up moving answers to sections where they were more relevant (thank goodness for the electronic version)…".

Being unwell or having other crises at the time of having to fill in the form created a particular need for support: a man who has learning disabilities/difficulties and sensory impairment said he "was in crisis at the time" and needed "considerable assistance" to complete his application. Some found it too distressing, confusing and/or difficult to tackle alone:

> *Too distressing to fill in alone, I don't even look at the form now (did for the first one, then asked for help as it was confusing) now I just give it (still in envelope) to Mind and they fill it in and ask me q's - though they have files from past ones also which speeds it up. I don't remember this difficulty with the old IB forms, I can't remember if I had help with those, if I did it would have been with a counsellor not a trained benefits advisor.*

However, help to fill in the form is not always easily available: "I am totally blind and asked for help from the local CAB to complete the form. I had to wait several weeks on an appointment and then another letter arrived from the DWP stating that the form had to be returned or payment would be stopped. This caused me a great deal of distress and anxiety. I called the DWP and explained my situation. They granted me another two weeks extra time to get the application for ESA completed."

6.2.5 Summary

Comments made by respondents reflect a general feeling that the questions illustrate a fairly set view of what determines a person's ability to work and that this often did not correspond with respondents' actual experiences or with what they thought was the likelihood of them being able to work. Many commented that the form was confusing and misleading, echoing the views of, for example, the National Association of Welfare Rights Advisors who are of the opinion that the questions are "simplified and misleading" and do not properly reflect the criteria used to determine eligibility (National Association of Welfare Rights, 2015). Respondents gave many examples of how the design of the form, and the questions asked, made it difficult to convey the experiences which made it difficult for them to do paid employment. Much of the advice about filling in the form, available from organisations such as the Citizens Advice Bureau, is aimed at mitigating these inadequacies of the ESA50 and helping claimants to provide information which would enable an understanding of their situation.

A long-standing criticism of the process of claiming ESA has been that it is not well suited to establishing the work capabilities of people with mental health conditions. This is confirmed by this survey: many of the comments on this first stage of the process - the ESA 50 form - concern how difficult it is to convey how mental ill health and/or fluctuating conditions affect the capacity to hold down a job. This echoes much of the advice from organisations, such as Mind and Rethink Mental Illness, about how to fill in the form, as well as the findings of each of the five independent reviews carried out of the Work Capability Assessment between 2010 and 2014.

6.3 The face to face assessment

The next stage of the Work Capability Assessment is a face to face interview, carried out by a 'health care professional' (HCP) employed by Maximus, the company contracted by DWP to carry out the assessments. The HCP uses, the previously discussed (see chapter 5) computer programme - the Logic-integrated Medical Assessment (LiMA) - to collect 'lifestyle data' and some

clinical information which is entered on the computer, mainly by pre-selected options. The only claimants who are not asked to attend a face to face assessment are those whose ESA50 form clearly indicates that they fulfil the criteria for the Support Group. As the assessor proceeds through the interview the computer programme gauges whether someone is 'fit for work'.

Most respondents had attended a face to face assessment and for more than half this had been within the previous three years. They were asked about how well the questions asked by the assessor enabled them to explain how their health condition, impairment or disability affected their ability to work, and how it impacted on their day to day life. This face to face assessment is the most important part of the process, the result of which will have significant implications for claimants and many explained how worried they were leading up to the interview. As one woman said, "What if they make me destitute?"

6.3.1 Positive experiences of assessments

Just over 1 in 10 (12.6 per cent) responded that the questions asked by the assessor enabled them to explain how their ability to work was affected by their health condition, impairment or disability. A similar per centage felt that it was evident the assessor had relevant expertise in their particular condition. One of the few people who wrote positively of her assessor, said she felt she "was very good at engaging and empathising." Slightly more people with physical impairments and/or chronic illness had positive experiences compared with people with a mental health condition.

Those who reported positive experiences often commented that they were interviewed by a doctor: for example, one man wrote that "I was interviewed by a Dr, who fully supported me explain the total extant of how my disabilities effect me. The associated report was detailed and accurate." Another respondent had a similar experience: "I was very fortunate with my 2nd WCA conducted by a Dr who clearly understood my conditions and, perhaps more importantly, how they impact upon each other". This is particularly interesting when considering, as discussed in Chapter 5, that the 'scientific and conceptual framework' assumes that assessors need not have any particular knowledge of

a claimant's condition or impairment and perhaps undermines their argument that this is not important.

The attitude of the assessor could make all the difference: "the assessor (a nurse) was very understanding and compassionate, to the point that because I was so traumatised, she felt that I'd been through enough just talking about my mental health without dealing with the physical, so she made a phone call and was given permission to end the assessment." Like some others who reported positive experiences, this respondent was put in the Support Group and it may be that getting an outcome which indicated that someone is believed and their barriers to work acknowledged affects how the Work Capability Assessment is perceived. However, it is not possible from the information gathered to look at whether there is such a correlation and it is certainly the case that many other people who commented that they were put in the Support Group were also very critical of the process.

6.3.2 Most people said that the assessment did not enable them to explain how their impairment/health condition restricted their ability to work.

Figure 3: How well did the questions you were asked enable you to explain how your health condition/impairment/disability impacts on your ability to work?
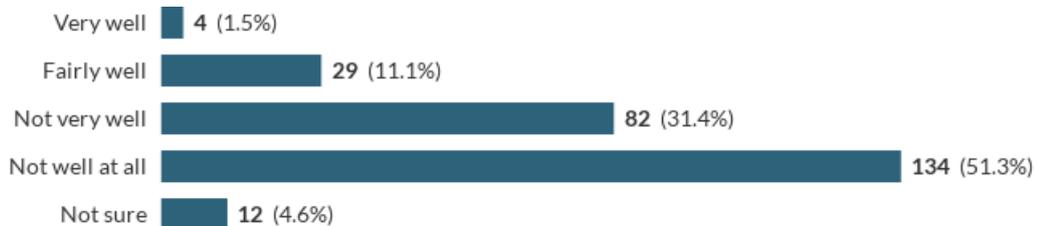
As with the ESA50 form, the most common criticism of the assessment was that the questions asked by the assessor did not enable people to explain how their capacity to work was restricted. This experience did not change much over time: of those who received their first WCA in 2008, 9 out of 10 responded either "not very well" or "not very well at all" to this question; for those whose last assessment was in 2016 8 out 10 expressed the same views.

People with learning disabilities/difficulties and/or visual impairments were the most likely to feel that the questions they were asked did not enable them to explain how their capacity for employment was affected (just over 7 out of 10) but this was not significantly greater than for people with physical impairments, mental health condition or chronic illness (just under 7 out of 10).

"There was no impression given at all that the questions were related to work. At no time did I feel that I had the opportunity to discuss how my condition affects my ability to work", wrote one respondent. The questions were focussed on specific tasks which many felt bore little relation to their ability to do an actual job. As one woman said: "I remember him asking me if I could pick up a penny. I can't think of a simple job where that would be my only working task. I wasn't asked about how I may or may not be able to do a job, it was all task based orientated, as if it was a given that they somehow related to work", while one man with a range of impairments and experience of ill health, wrote "they never delved into the more serious issues I have to deal with as a result of brain tumours and how it affects my day to day life….They were only interested in yes/no answers to seemingly satisfy their set questions."

Some respondents wrote of how the questions, and tasks they were asked to demonstrate an ability to do, were both inappropriate and irrelevant: one respondent who has both a physical and a hearing impairment described how "I was asked really dumb stuff that had little if any resemblance to how the disability affects my ability to manage on a day to day basis. For example, I've never been able to touch my toes so asking me to do so to measure my disability is just silly because I've never been able to do it. Also never had a job where touching my toes is part of the job description or required during the course of the average working day".

"All [the questions] were concerned with everyday life outside the workplace" wrote a man with a mental health condition, echoing the concerns expressed by many, including a woman with a long-term health condition, "The assessment does not discuss work and is not a test of specific employability".

6.3.3 Quality of the assessment

When the DWP carried out an 'evidence based review' of the Work Capability Assessment in 2013, a semi-structured interview approach was tested and found to be preferred by applicants (DWP, 2013). The last independent review reported that "DWP will explore practical improvements to the assessment process in light of the EBR findings, in particular the feasibility of healthcare professionals using prompts from a semi-structured topic guide for WCA discussions" (Litchfield, 2014, p 30). The current guidance for WCA assessors stresses interview skills of, for example, 'active listening', 'effective questioning' and 'listening between the lines' (Centre for Health and Disability Assessments, 2018. p.55). However, since the assessment is still using a computer programme which requires assessors to select pre-determined 'one click' options from an on-screen menu, it is probably not surprising that many of the respondents to this survey found the process very mechanistic: "They basically just go through the form again and ask all the same questions. They show no real interest in finding out about your condition and how it affects you. They ask a question, get an answer, move onto the next question. There is no discussion, just checkboxes". "A tick box exercise" was an expression used by a number of respondents.

A very common comment was that assessors spent most of the time typing answers into their laptops/computers which made respondents feel a lack of engagement and, for some, hampered their ability to fully explain the impact of their condition: "Felt like the assessor was more interested in typing my answers than actually listening to me properly" wrote one woman with multiple impairments. Another described a similar experience: "The assessor seemed to spend more time looking at the laptop, and typing things, than actually giving me the time I needed to formulate my responses to the questions asked and, due to pain, fatigue, and chronic memory problems, I couldn't think clearly enough to give any sort of detailed answer to what questions were asked."

Some people had difficulty understanding the questions or felt they needed to use medical terms that they weren't necessarily familiar with. Others felt they weren't given time to explain what their condition was and how it impacted on

them: "I felt I was being hurried when trying to explain a mental health complex issue". A woman with both physical and sensory impairments and mental health condition said: "I am no good at communications with people i do not know i get nerves and anxious when talking to people i do not know and do not come across clearly and i also get flustered". A number said how much pressure they felt by the way the assessment was conducted: "It was rapid fire, I couldn't think straight, or recall and the pressure to answer or find answers to the many questions left me numbed, I just couldn't process any more, my mind went blank, as it usually does under pressure."

Although the assessment of performance of tasks should be about whether these can be done reliably, safely and repeated, some people found the assessor focussed more on "just whether things could be done." Others described how, for example, "Being able to raise my hand doesn't equate to being able to do it all day or to lift things or that I get tired". However, they felt, "they don't want to hear that". One woman who has both a learning disability/difficulty and mental health condition wrote that in her experience, "The questions focused on supposed ability to perform tasks but not the implications of performing those tasks or how long it takes to perform them and how much preparation and time to recover after do you need". The after affects of doing an activity - and the failure of the assessment to include these - was an issue raised by people across a range of impairments. "It does not cover the after affects, it simply covers doing it in the first place", said a woman who has autism and mental health difficulties.

Many respondents worried that the assessor lacked knowledge about their impairment and its impact. One respondent wrote of how the assessor didn't understand the different types of epilepsy and "their related triggers or seizures." Another said, "The Assessor confessed she hadn't heard of my condition, …and clearly found it difficult to understand how it impacts on my life." Some respondents commented that they had expected the assessor to have informed themselves about their condition prior to the assessment: "They had no knowledge of a medical condition I have, which admittedly is quite rare, but I expect them to at least attempt to research it as they have prior knowledge of all health problems to the assessment".

One woman told of how she was disconcerted that "The assessor seemed uncomfortable about my Deafness and kept talking to the person who accompanied me about the elderly people they'd encountered with age-related deafness and how they seemed able to hear but used it selectively. They did not seem to be saying this unkindly but it was awkwardly inappropriate and was clear they did not know how to handle my level of deafness - which is not age related nor am I elderly". Unsurprisingly, "it felt like talking to someone who'd never met a deaf person before".

Assessments could feel inappropriate to the barriers faced "The woman made me walk up and down the room, something I said I could do, it seemed pointless" wrote a respondent, while at the same time she felt "It was very difficult to show how my mental health affected me…and hard to talk about fluctuating conditions".

Some people received physical examinations by the assessor and some expressed concerns about these, particularly if they thought the assessor was not qualified to carry out such examinations. This was one man's experience, who wrote "The assessor did some basic tests on joint strength. I was unhappy performing them without knowing the assessor's qualifications. While the tests didn't cause me any pain they were on the threshold of being uncomfortable and I was glad I had someone with me for moral support. I think assessors should be forbidden to touch people in these sessions.…".

A young woman with learning disabilities/difficulties and sensory impairments wrote of how she wanted to be put in the Work Related Activity Group as "I wanted support back into work". However, she too had the common experience of conclusions being drawn which did not fit into her own assessment of her situation: "I was told I was not fit to work and the assessor would recommend I be put in the Support group. She did not take into consideration that I could find employment around my disabilities".

An issue which received some publicity early in 2017 was also highlighted by a few respondents in this survey. The Handbook issued to Health Care Professionals states that they are required to assess the risk of suicide or self-

harm, stating "You should explore the claimant's mental state during the assessment, including thoughts of self-harm or suicide" (Centre for Health and Disability Assessments, 2018, p. 256). It would appear that, in a section asking about suicidal thoughts, assessors ask: "And what is it that stops you from acting on the thoughts that you have?" and "Can you think of any reason that you're not doing that? Is it friends or family support?" (Pring, 2017). The computer-generated nature of the interviews may contribute to some people reporting that they were asked why they hadn't killed themselves: "I'd put down that I'd had some suicidal thoughts. I was asked why I hadn't killed myself yet.", wrote one. "Questions were rapid and blunt eg "have you ever tried to kill yourself and when?" I broke down after this and found it difficult to continue but told I had to continue even though I didn't think I could accurately answer any more questions, I don't remember anything after that."

Applicants are able to request a copy of their report and a third of respondents did so although over 4 in 10 said they did not know they could ask for one. Some people didn't want to ask for the report, sometimes because they were worried such a request would "bring extra attention onto me" while others thought they might find it too distressing: "I did not wish to see it, as the whole process was traumatic enough without seeing the report". Of those that received a copy, 7 in 10 felt that it reflected their information either fairly poorly or very poorly.

Figure 4: If you did receive a copy of the Assessor's Report how well did it reflect the information you gave during the WCA or on your ESA50 form?
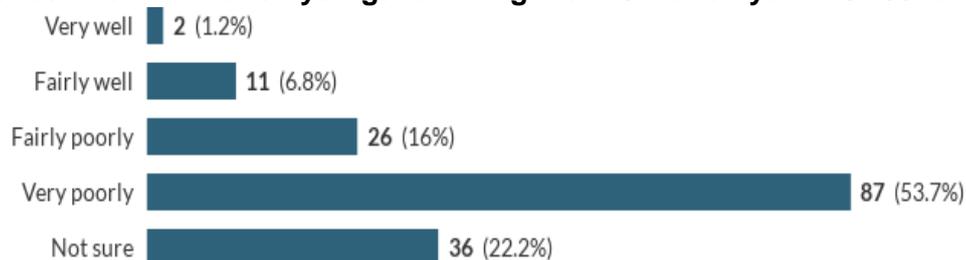
The fourth independent review of the WCA had recommended that claimants should be able to see what is written during the assessment - as the fifth independent review said: "This appears to be a simple remedy to a common

complaint that testimony is recorded inaccurately" (Litchfield, 2014, p.21). Nevertheless this recommendation has not been implemented.

6.3.4 Respondents with a mental health condition expressed particular criticisms of the assessment.

As mentioned above, a third of respondents described their impairment as a mental health condition. As with the ESA50 form, many respondents felt that the focus of the face to face assessment was primarily on restrictions related to physical impairments and illnesses: "My reason for being incapable of working was related to my mental health" said one woman and yet, "they had me bending and doing simple vision tests." Respondents found there was no opportunity to explain the impact of their mental health condition on their workplace experiences: "My condition specifically unable suffering extreme anxiety in the workplace due to previous trauma and there were no questions about this, all were concerned with everyday life outside the workplace"

> *All the questions were about things like making cups of tea and emptying the dish washer. This didn't help explain my mental health problems.*

> *They asked about a bunch of mobility stuff, and only towards the very end did they ask about mental health issues.*

A small number felt that the assessor was sympathetic but that the problem was with the pre-set questions: "The assessor was nice but the assessment didn't feel very thorough. My condition was work-related stress and there weren't many relevant questions". Another said the assessor "only asked questions that didn't help explain illness."

This is an understandable outcome of an assessment process which, as Chapter 5 showed, aims to examine an individual's 'functional capacity'. Although there are two regulations (29 and 35) which allow an assessor to consider the impact of either work or work related activity on an individual's health, as mentioned in chapter 3, the DWP reissued guidance on these in 2015 with the aim of reducing those being placed into the Support Group under these regulations (Department of Work and Pensions, 2015a). The reasoning given for this was that any potential harm that someone might experience if

they were expected to work would not exclude them from Work Related Activity as:

> "The flexibility in the DWP approach, tailoring work-related activity to each claimant's circumstances and health condition, and the requirement that claimants must not be asked to do anything that could put their health at risk, make it unlikely that many claimants will be at substantial risk if required to carry out work-related activity." (Centre for Health and Disability Assessments, 2018, p 257)

This is interesting in itself as it appears to be an acknowledgement that work-related activity may be disabling and harmful in some way, but that it might be possible to make adjustments to reduce this. However, there is no clarification of what adjustments would be made to ensure work related activity does not replicate the potential harm that work may cause, and it is very difficult to see how a claimant could challenge any Work Related Activity they might be asked to undertake without the risk of being sanctioned. It is also not clear what training any job centre staff would have in understanding how particular impairments may impact on claimants' ability to do certain activities or whether they would be aware of those claimants who were placed in the WRAG for this reason. My own experience of being in the WRAG group and interacting with Job Centre staff suggests that in practice they simply would not have the time to explore these issues and put adjustments in place. However, this is an area which undoubtedly needs more research.

The focus on abilities to physically carry out tasks could mean that the experience, as one man said, "Made me feel like a fraud." The pre-set categorisation of experiences could also mean that assessors' conclusions do not reflect what someone feels their experience to be. For example, one young man wrote of how "They asked how often I had good days or bad days. I said I had quiet days maybe for one week and bad days for sometimes several weeks at a time but never good days. The OT decided this meant I had good on average 2 days a week."

6.3.5 People with fluctuating and/or multiple impairments found particular problems

Many respondents felt that the questions asked by assessors do not take account of interacting and fluctuating conditions and their impact: "I have a fluctuating neurological condition, and all the questions are very black and white and do not account for fluctuation, or the fact effects of various activities can be cumulative, so I can do x and y, but not on the same day, but it is recorded that I can do both x and y no problem because there is no room for this basic nuance."

"My condition is cumulative and fluctuating. An activity on one day impacts my ability to perform activities for days or weeks afterwards. Independent of this, my condition changes without warning, day-to-day. The WCA considers neither factor." A number of respondents pointed out how inappropriate it was to assume that someone with a fluctuating condition could give a definitive answer: "I was asked about an 'average' day and I was not listened to when I said my condition was very variable, I was told to just imagine an average day anyway". One woman pointed out experiences of ill health can be impacted by a range of circumstances: "I have physical, medical and mental health problems, they all tend to affect each other and also have triggers such as stress, pain, illness (ie. Viruses) it's impossible to predict or quantify how it all effects my daily life. The [questions] are structured to have definitive answers."

What respondents felt were the inadequacies of the assessment to acknowledge fluctuating conditions could also make them feel the validity of their experience was undermined: "Again the very fact that my illness is so variable is one of the reasons work has been very hard for me and this was not understood. I felt like I was lying if I said everything was like my bad days but if I admitted to good days I was scared I'd be judged fit based on these."

Maximus - the company carrying out the WCA - has recently issued new guidance on assessing people with fluctuating conditions in an attempt to better understand whether "activities can be reliably, safely and repeatedly undertaken" (Maximus, 2017). Although this is a welcome change it is unlikely to make a noticeable difference as the assessment is still grounded in the

theoretical framework which treats these conditions as 'contentious' (as shown in Chapter 5) and the policy motive behind the assessment remains that the numbers of claimants needs to be reduced in order to bring down public spending and expand the reserve army of labour (as shown in Chapters 2 and 3).

6.3.6 Summary

Most of the responses concerning the face to face assessment echoed the negative experiences of the ESA50 form. Respondents wrote that the questions asked were not relevant to them nor did they allow them to explain how their health condition/impairment impacted on their ability to work. There was also evidence of the difference having a sympathetic assessor and/or one who had expertise in the respondent's health condition/impairment had on their experience of the assessment. As discussed above, a number of people wrote of how distressing the entire experience was. People with mental health conditions and those with fluctuating conditions reported how the format of the interview and the questions asked were often unsuited their particular experiences and could make them feel "like a fraud". Such experiences are unsurprising, given that the framework underpinning the WCA is underpinned by the notion that some incapacities are a matter of 'choice and intent' and that claimants experiences of their health conditions/impairments should be considered contentious, as described in Chapter 5.

6.4. What kind of questions would have elicited the information necessary to better gauge impact of impairment or illness?

The focus group interviews had been dominated by discussion of how inappropriate the questions asked in the Work Capability Assessment were for determining a person's ability to hold down paid employment. It was therefore decided to ask survey respondents what alternative questions they felt might have been more appropriate. Most responses repeated their negative experiences of the questions they had been asked but the most common response from those that did cite possible alternatives made suggestions about both the style of the interview and its content.

It has already been mentioned that the style of the interview - determined as it is by a computer programme - is generally felt to be unhelpful and some people made suggestions for a better format. One woman, who accompanied her husband to the interview and completed the survey about his experience, expressed the opinion that: "If they had been given the time to be able to get to know my husband, even a little - to be able to calm my husband, and even befriend him enough for him to trust the assessor somewhat, the assessment may have gone a lot better." Another respondent also felt that the way the interview was carried out could have been improved: "Explain what it was all about and try to stop me from being scared and worrying they were just going to stop my money". One woman said, "She could have treated me with compassion as another human being from the beginning. Tried to put me at my ease and diffused the situation instead of telling me to 'calm down'. She could also have referred to the answers on the form and said something along the lines of 'I see on your form you say….' Could you tell me a little more about this'".

A number of other suggestions for improving the content of interviews related to giving people the opportunity to explain how their impairment and/or illness specifically affected them. This was felt to be particularly important if the assessor did not have expertise in the person's particular impairment or illness, but others also made clear that it was important because experiences could vary. One person said simply asking "How does my disability affect me?" would have been helpful.

A number of people wrote that they should have been given a chance to, in their own words, explain the impact of their impairment, disability or illness: "Giving me a chance to talk about my problem would have been good". "There needs to be a genuine conversation about the person and how their conditions impacts their lives" wrote a man who has both physical and sensory impairments. These sorts of responses echo the recommendation from the first review of the WCA in 2010 but which was not taken up by the government.

Others wrote of how the questions could have been more appropriate, for example by being related to previous experiences of work and what had made them give it up: "She could have asked about my previous work experiences

and what made me have to give up those jobs….She could have asked what I'd found made it hard for me to work.."

The process of claiming ESA has often been criticised for taking no account of the support that many disabled people would need to increase their chances of employment. Some respondents similarly felt that a more realistic assessment would have taken account of the support that might be needed to enable them to gain and retain employment: "They could have asked what I felt would be needed to open up the opportunity to work…They could have asked about support and if it had ever been available".

Respondents were also asked whether they were currently in paid employment (full or part-time) or voluntary work. Just over one in ten reported that they were working either part or full-time while almost a quarter were doing some voluntary work. They were asked what factors had made this paid or voluntary work possible and the most important factors reported related to working patterns and the attitudes of employers and fellow workers.

Conclusion

The fifth, and final, independent review of the WCA expressed concern that "perceptions of the WCA remain overwhelmingly negative" (Litchfield, 2014, p.5) and this was certainly confirmed by the majority of respondents to this survey. The experiences of WCA assessments described by respondents range from the years 2010 to 2016 but the criticisms are remarkably consistent.

Responses to this survey indicate that the format of the WCA is felt by most of the people going through it to be inadequate to the task of assessing whether they are likely to be able to work. Two main reasons emerge from the data: firstly, that the WCA does not gather information related to the practicalities of paid employment; and secondly that the format of neither the ESA50 form nor the face to face assessment enable people to provide the information they felt assessors needed to know. An analysis of successful appeals against ESA decisions, carried out in 2012, indicated that the most common reason for overturning the DWP's decision was that the applicant was able to provide the Tribunal with oral evidence that supported their appeal (DWP, 2012, pp.5-6). A

number of changes have been made to the WCA process since its introduction, yet respondents whose experiences of the WCA span the years 2010 to 2016 reported remarkably similar difficulties and criticisms.

The experiences of focus group, interviews and survey participants all illustrate the reality of an assessment which, as Chapter 5 described, is based on the assumption that an individual's 'subjective' experience of their impairment/health condition is contentious. Several participants felt that assessors were trying to 'catch them out' or were made to feel as if they were 'scroungers' or 'fraudulent'. Moreover, the WCA's 'objective' functional test aims to remove the need for any specialist knowledge about an impairment or health condition on the part of the assessor, and this results in a failure of assessors to understand, or record, the impact of a particular impairment/health condition on someone's ability to work. This is exacerbated by the refusal to consider the type of work available and how an individual's impairment/health condition might make it difficult, if not impossible. Barnes and Sissons (2013) research, which is discussed in Chapter 3, suggested that in practice this can mean that most disabled people found 'fit for work' are unlikely to actually obtain employment.

It is the contention of this thesis that the experiences of research participants, presented in this chapter, are directly related to the motivations behind the reforms to out of work disability benefits, as described in Chapters 2 and 3, namely governments' aims of cutting the numbers qualifying in order to both reduce public expenditure and expanding the active reserve army of labour. However, while this lived experience of the WCA needs to be heard, further analysis is required in order to interrogate the relationship which is being played out in the context of this validating device. It is this which is the subject of the next chapter.

Chapter 7: "Why do they think I am a scrounger?"

Introduction

When this research started, one of the key questions was whether a disconnect exists between the administrative category of disability (as defined in the context of the benefits system via eligibility for ESA) and disabled people's lived experiences of how their impairments/illness impact on their ability to work. Since then it has become increasingly clear that the answer to this is yes and as such the research has developed to examine why and how this disconnect has occurred and how it presents itself.

As we have seen, the Work Capability Assessment operates as a 'validating device' for determining, and governing, the legitimacy of a person's claim to be unable to take up or continue paid employment and, thus, to be entitled to an income replacement benefit. The WCA is therefore the most prominent current validating device which determines the administrative category of 'disability' among working age people in the UK. It determines not only who is recognised as exempt from waged labour but also confers a particular social status identifying who is 'deserving' or 'undeserving' of assistance from the State. It also acts as a device to enact labour discipline by both working as a mechanism to help control the active reserve army of labour and using the principle of less eligibility to deter people from claiming

Chapter 5 explored the development of the thinking behind the 'theoretical and conceptual framework' for the WCA, identifying that it is underpinned by treating what are identified as 'common health problems' somewhat differently from 'severe and permanent impairments', and by the assumption that people's own accounts of their restrictions are contentious. That chapter also examined the implications of this for the methodology of the assessment. Chapter 6 used the data generated by the focus groups, interviews and survey to provide a descriptive account of people's experiences of both filling in the ESA50 form and going through the face to face interview which together make up the Work Capability Assessment.

This chapter comprises an interpretive reading of the same data, "reading through and beyond the data" (Mason, 2002, p.149) in order to understand the relationship that is being played out in the WCA process.

7.1 An unequal relationship

There's also the constant anxiety that the reassessment letter will arrive at any time from just a couple of months after the award. This worry is there every day, because I could suddenly be deemed 'fit for work' and lose everything at any time, even though I am not able to work to support myself, as much as I've tried and would like to.

The WCA process involves state employees (DWP 'decision-makers') and employees of an organisation contracted by the state ('Health Care Professionals') making judgements about the impact of a person's impairment and/or illness on their capacity for work. These judgements have considerable consequences for people's lives: they determine whether a person is coerced, through 'conditionality' to 'prepare' for work or to seek work, and how much of an income replacement benefit they receive. For some people, a WCA which determines they are 'fit for work' results in no income at all if they are unable to comply with the conditionality imposed on JSA claimants (see for example, Mcdougall et al, 2015).

There is a long history of professionals and bureaucracies having power and control over disabled people's lives, where professionals 'assessing' disabled people are viewed as the 'experts' and disabled people as dependant on them for help rather than as having crucial expertise about their own lives and experience. In 1981, Allan Sutherland wrote of professionals "cutting us out of decision-making processes, either by a simple rejection of consultation, a refusal to recognise our right to be involved in decisions being made on our behalf, or, more subtly, by conducting public discussion in ways that exclude us…" (Sutherland, 1981, p.129). Sutherland was writing at a time when disability was increasingly being redefined by disabled people as a civil rights issue and, as French and Swain identify, this was accompanied by fundamental challenges to professional ideologies and the traditional relationship between professional and 'client' or 'patient' (French and Swain, 2001).

According to a disability rights perspective, this traditional relationship is characterised by an unequal power relationship, stemming from a body of knowledge and expertise held by the professional, where the 'objectivity' of professional judgement is distinguished from the client/patient's 'subjectivity'. This power relationship is also central to the theoretical framework of the WCA which views the disabled person's experience of their health condition/impairment as subjective and contentious and that of the assessor and Decision Maker as objective. As was discussed in Chapter 5, Waddell and Aylward argued that people's 'subjective' descriptions of their health condition/impairment should not be relevant in an 'objective' assessment of their ability to work.

One of the key features of the relationship between disabled people and professionals, identified by both French and Swain (2001) and Oliver and Sapey (1999) is "the pathologising and individualising of problems that have been socially and economically created" (French and Swain, 2001, p.736). In these previous critiques of the relationship, professionals are identified as operating a medical or individual model, with an emphasis on identifying what is 'wrong' with the individual's body and the solutions being offered are those of treatment and rehabilitation, both of which are in the control of professionals. In the case of the WCA, the 'professionals' given the power of defining an individual's experience are, of course, the assessor and the Decision Maker rather than any professional with expertise in their particular impairment or condition, but they too are using an individual medical model approach with a focus on functional limitations and a failure to consider any social or economic factors.

Oliver's analysis of the relationship between the social work profession and disabled people illustrated the inappropriateness of assessments which focus solely on levels of impairment, assuming that there is a direct relationship between the extent of impairment and the level of need. In contrast, he said "The social model…suggests that there is no such direct relationship: someone with a very severe impairment may only be mildly disabled, whereas someone with a minor impairment may be totally disabled by poverty, poor housing, the attitudes of employers or hostile social treatment" (Oliver, 1983, p. 120).

Like Sutherland, Oliver identified the damage done by medical and social care professionals who concern themselves "with purely mechanical questions of the way the body functions, with little sensitivity to people as people" (Sutherland, 1981, p.119) and the alienation this creates for disabled people. As we have seen, the WCA is similarly concerned with functional capacity and, as such, the social and economic context which influences the likelihood of obtaining employment is treated as irrelevant. This failure to consider factors such as whether people have necessary qualifications and experience, whether employers are likely to discriminate against them or provide necessary equipment or adjustments to the environment and working conditions, and whether there are relevant local vacancies to be filled, has in fact been apparent since the All Work Test was introduced in the 1990s, as discussed in Chapter 3. The WCA, however, is in addition based on a set of assumptions about the roots of incapacity, as described in Chapter 5. While Waddell and Aylward's 'theoretical and conceptual framework' recognised the relevance of combining three models of disability - biological, social and psychological - it was also based on the assumption that the 'common health problems' exhibited by the majority of people applying for out-of-work disability benefits often have no discernible bio-medical cause, and that it is individual attitude and motivation which primarily influences capacity for employment.

These underlying assumptions of the WCA mean that the judgement of the assessor, and that of the computer programme, are privileged over the experience and judgement of the person who actually lives with the impairment and/or health condition. The result, for many of the respondents to this research, was an experience of conflict between the judgement of the professional and that of the person being assessed. Of those who requested a copy of the HCP's report, less than 1 in 10 thought that it fairly reflected what they had told the assessor, and it was notable how many times respondents who had received a copy of their assessment report felt that it didn't reflect what they had told the assessor.

The written report didn't match what we said in the assessment.

The answers on the report did not reflect what I said at all.

This could be taken to be a misreporting by the assessor and some people did in fact accuse assessors of inaccurately recording what they said. However, given the theoretical framework behind the assessment, it is also likely that the information provided held a different meaning for the assessor than it did for the person being assessed and, arguably, it is the very nature of the assessment that makes such a discrepancy likely. As we have seen, the assessment involves questions and observations about functional limitations, with the LiMA programme suggesting 'logical' outcomes which, from the experience of respondents to this research, often seem at odds with the person's reality. The training programme for WCA assessors (discussed in Chapter 5), and the testimony of whistle-blowers (see, for example, Jones, n.d.), illustrate how assessors are required to focus on supposedly 'objective' measurements rather than on what the claimant tells them. For example, observing that a person hears their name being called, rising from the chair in the waiting room, reading a paper while waiting are all recorded as indications of functions being assessed.

My report agreed I had issues with my back and legs but then stated I was fine walking.

My condition causes severe, constant pain. The report said clearly that my movements were pain free.

The assessment is concerned with answers to the questions being asked and not with what the person being assessed thinks is relevant to their ability to work. This may also account for the seeming discrepancies between assessor's reports and conclusions and the disabled person's experience of the assessment. As written evidence to the Work and Pensions Committee from a palliative care worker described:

I have attended face-to-face assessments with patients/clients and have observed that there are set questions which the assessor will be asking which often bear little or no relation to the lived experience of illness and disability and that there is no attempt made to write down anything the

claimant will say about their situation unless it is prompted by one of these set questions (Anonymous, 2017, p.5).

Attending the assessment itself can be taken as evidence of function. One respondent's report stated: "*Even though she was accompanied by her son she was able to attend the assessment*" and people with mental health conditions may find that even being able to participate in the assessment without showing visible distress is taken as evidence of being able to function sufficiently to be 'fit for work' or for work-related activities.

In the report he stated that I was not distressed during the interview.

This does not mean, however, that an assessment carried out by a 'professional' is inevitably alienating or disempowering for a disabled person and Oliver does not deny the relevance or the value of people with professional expertise. As he says,"I have not written..from an anti-professional position because I believe that disabled people should be entitled to the very best and most appropriate professional intervention in our lives and that disabled people and professionals exist in a state of mutual dependency" (Oliver, n.d. pp 5-6)

The possibility of a more facilitative and partnership approach is illustrated by a small number of the respondents who described a rather different experience from the 'tick box' exercise that the assessment essentially is.

On this sole occasion I was interviewed by a Dr, who fully supported me explain the total extent of how my disabilities effect me. The associated report was detailed and accurate.

The assessor was actually sympathetic to the fact that the computerised question set did not reflect the reality of my condition, and instead filled in details about me rather than ticking yes or no boxes

Such descriptions echo, for example, Finkelstein and Oliver's writings, where they describe how professional expertise can be used to assist disabled people to identify what their barriers and needs are (Finkelstein, 1999; Oliver, 1983). The important point is, however, that in order for professionals to work in a way which empowers, rather than disables, it is necessary "To recognise clients'

experiential knowledge as the foundation for learning, with the professional's expert knowledge at the *service* of the client" (Williams, 1993, p.12). In contrast, the WCA not only privileges the assessor's judgement over that of the disabled person but, being grounded in the version of the biopsychosocial model put forward by Waddell and Aylward and adopted by the DWP, it has an inherent tendency to treat the disabled person's assessment of their difficulties with some scepticism, particularly in the case of the three 'common health conditions' much discussed by Waddell and Aylward.

7.2 Denial of agency

A denial of agency is a key part of the unequal relationship which is at the heart of the experience of the WCA. Agency, or self-determination, has been a crucial part of the movements for disabled people's civil rights: as Duffy wrote, "Put simply, if you have self-determination then this means you are in charge of your own life. If you do not have self-determination then other people are in charge of you" (Duffy, 2003, p.5). A paper prepared for the Disability Rights Commission identified that the ability to both participate in, and contribute to, society depends - for disabled people - not only on the rights to the removal of barriers and the support necessary to participate and contribute, but also on active involvement in how barriers are removed and support is provided - it is this choice and control which delivers self-determination (Morris, 2005, pp. 7-15)

In the context of the support needed to go about one's daily life, disabled people have campaigned vigorously for this right to make choices. The rationale for providing cash payments in lieu of social care services (direct payments) was that disabled people know best how to meet their needs and that having control over the support required was necessary in order to exert the same levels of choice and control - the same levels of self-determination - that non-disabled people experienced. The success of such campaigning was reflected in the government strategy adopted in 2005 which set out the commitment that "By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society" (Prime Minister's Strategy Unit,

2005). Internationally, it culminated in Article 19 of the UN Convention on the Rights of Persons with Disabilities:

> States Parties to the present Convention recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community.

The recognition of and support for self-determination is, however, completely lacking in the experience of accessing for ESA. As pointed out by Sutherland and many other disabled people "the very simple fact that we are, inevitably, the experts on the precise effects that our disabilities have on our bodies" (Sutherland, 1981, p.127) means that disabled people tend to end up being experts on their own conditions and this is extended to understanding what the difficulties and barriers to work are, and how realistic it is to engage in waged work. However, the experience of respondents to this research illustrates that the experience and expertise of the individual themselves is largely removed from the process of deciding whether someone is 'fit to work' and entitled to an income replacement benefit. The disconnect between the way the WCA assesses 'work capability' and how disabled people themselves judge the impact of their impairment and/or illness is illustrated, for example, by one respondent who, although placed in the Support Group, found that the reasons for this did not accord with her own judgement about what affected her capacity for work:

> *It was almost like reading a report from someone else's assessment. It bore little relation to my conditions or what I'd said during the interview. Emphasis was put on things that were largely irrelevant while some of the most important aspects of my condition and how it affects me were ignored. The supporting evidence from my GP, specialist and physio all appeared to have been ignored as I got no points for a serious long-term back injury that affects my life on a daily basis. However, as I got enough points to be put into the Support Group, based on the seriousness of my*

depression, I did not appeal. There was a real risk, in doing so, that I could end up worse off.

When a disabled person's expertise in how their illness or impairment affects them is ignored, this failure to acknowledge their everyday reality is compounded when there is a clear message of distrust.

The most dehumanising process I've ever experienced. It felt like a system based on distrust, having to prove an illness(es) that they didn't want to see. My first assessor laughed out loud and said 'That's not a panic attack ' when I described my symptoms of anxiety.

'Observation' of how people behave before and during the interview (as discussed above) is part of the assessment process and seems to be considered as more valid than information conveyed by the claimant themselves.

They watch you constantly……but they asked very little about my specific conditions and how they affect me.

Some people are aware that the way they appear is not indicative of their actual experience of their bodies and wrote of how this makes it difficult to get over to the assessor the reality of their illness and/or impairment.

I just felt I had to exaggerate my condition to suit their points system…..I look really healthy and am very able to 'hold my own' and converse intelligently and that is a disadvantage in this situation. I am a very strong mentally person and people think this makes you able.

In the case of people with mental health difficulties such as anxiety and depression, appearance and/or the ability to describe the restrictions experienced may itself be taken as undermining the validity of the information presented.

The assessor's report mentioned that I was well presented and well spoken, in a manner that suggested it counted against me. Almost as if I

was expected to have a seizure, a panic attack or be overcome by depression during the meeting.

The fact I was given a '0' for my mental health restrictions suggests that either the questions asked weren't ideal, or my responses weren't taken seriously. I explained how depression and anxiety makes communication with people almost impossible, means I cannot cope in group environments, makes leaving the house incredibly difficulty etc and yet was not awarded any marks under that section.

Many disabled people want to engage in paid employment but recognise that they need support and/or changes to the working environment in order to do this. However, as the WCA is confined to assessing functional limitations it is unable to recognise the potential for employment where disabling barriers are removed and necessary support provided.

I asked to be put in the work group as I wanted support back into work. I was told I was not fit to work and assessor would recommend I be put in the support group. She did not take into consideration that I could find employment around my disabilities.

Participants in this research illustrated again and again how to enter the social security system as someone who has difficulty working because of impairment and/or illness means entering a system where people feel a dramatically diminished control over their lives. This taking away of control stems not just from the denial of their own experience and expertise but also because the way the system is administered creates continual uncertainty and anxiety:

There's also the constant anxiety that the reassessment letter will arrive at any time from just a couple of months after the award. This worry is there every day, because I could suddenly be deemed 'fit for work' and lose everything at any time, even though I am not able to work to support myself, as much as I've tried and would like to.

The whole experience takes months and it really made my mental health worse dreading the letter through the door.

My second appeal took eleven months, which is a long time to live with uncertainty.

You were given no information of how long it would be, it was utterly, utterly, ridiculous. I needed additional medication to help deal with the anxiety

As Chapter 5 identified, the model which underpins the WCA emphasises the role of 'free will' in the experience of the 'common health problems' found amongst people on and applying for IB/ESA and, in fact, it has been argued, the model "attributes almost all the causal role to individual agency" (Shakespeare et al, 2016, p. 40). Yet the denial of agency - a denial of being 'in charge of your life' - was a very common experience amongst those who responded to the survey. The ability to judge whether they were able to work and/or if they required support in order to work (and what kind of support) was transferred from the individual themselves to the assessor and the Decision-Maker acting on behalf of the State, with very little, if any, credibility or importance given to the person's expertise and experience. This meant that - in the context of ESA eligibility - the State, rather than the disabled person themselves, was totally 'in charge' of defining the experience of impairment and/or illness and its impact on the ability to work to the extent that disabled people's individual agency is largely denied.

7.3 Disconnect between the world of work and what the WCA assesses

The denial of agency was particularly expressed in respondents' feelings that the assessment took little account of individuals' own assessments and experiences of the world of work.

No weight is applied to the likelihood of anyone employing you only that theoretically there could be a job that you might be able to do

No questions were asked about my work ability, only my day-to-day activities. Since I was capable of making myself a cup of tea I was capable of full-time work.

In the last one I had, I remember him asking me if I could pick up a penny. I can't think of a simple job where that would be my only working task. I wasn't asked about how I may or may not be able to do a job, it was all task based orientated, as if it was a given that they somehow related to work.

A key conclusion from the last chapter's analysis of respondents' experiences was that, from their point of view, the WCA does not actually assess the likelihood of someone being able to engage in waged employment and that this is because the assessment is of functional limitations which bear little or no relationship to the practicality of either doing an actual job or getting and retaining a job. As we have seen (Chapter 3), the availability of suitable local employment opportunities was removed as a relevant factor in the 1990s when the All Work Test was introduced and disability organisations at the time argued that the new assessment criteria failed to take into account either the availability of employment or the likelihood of the individual being offered employment.

Thus, many respondents expressed a sense of dislocation between their experiences and the way the assessment was carried out, with a particular emphasis on what seemed to them the irrelevance of the functions being assessed to the actual ability to hold down a job.

Totally inappropriate questions for help getting a job. Picking up coin, placing items in coat pocket. Picking up carton.

What's with the 'being able to hold a 1/2 litre of milk' got to do with any real job, for heaven's sake, let alone being able to pick up a coin from a surface!

I was asked really dumb stuff that had little if any resemblance to how the disability affects my ability to manage on a day to day basis. For example, I've never been able to touch my toes so asking me to do so to measure my disability is just silly because I've never been able to do it. Also never had a job where touching my toes is part of the job description or required during the course of the average working day. In other words, the

questions asked were clearly designed by someone who is not disabled and has no experience of disability and have zero relationship to whether or not someone is capable of working

From the point of view of respondents, their experiences of both the form and the face to face assessment illustrated the inappropriateness of assessing eligibility for out-of-work disability benefits on the basis of functional limitations. Many of their responses echoed Oliver's point (mentioned above) that impairment and illness are not experienced in a social vacuum.

This government and the assessment process don't understand impairment at all. How it impacts on our daily life, how we view the world with it, and the barriers we face on a day to day basis.

You need someone to look at everything - how Access to Work comes in, employer discrimination, they shouldn't just focus on a work capability assessment. To me, it seems employers don't want me. The focus should be on employers. And also the assessment questions should look at issues relating to what you need to work.

How many employers would have with someone with schizophrenia in the workplace with the media negativity schizophrenia in the press.

Over the years since the WCA was introduced, there have been many criticisms of how effective the assessment is in judging the likelihood of a person being 'fit for work'. Much of the evidence points to a significant discrepancy between the type of judgements that are made and the reality of people's limitations. For example, the House of Commons Work and Pensions Committee received evidence from Work Programme providers in 2013 that many people who had been on Incapacity Benefit and had been assessed as fit for work were in fact not able to work (House of Commons Work and Pensions Committee, 2013, paras 80-89) and the impact of impairment and/or illness on the reality of finding and retaining employment was further illustrated by an Evidence Based Review where expert panels identified that 83 per cent of claimants deemed fit for work would need "on average, two or three" adjustments; 50% would need flexible working hours; and 24% would need a

support worker (House of Commons Work and Pensions Committee, 2014, para. 130).

7.4 Institutional stigmatisation

The tendency to treat people's own assessment of their difficulties with scepticism - which is a central component of the WCA's theoretical framework - contributes towards respondents' feelings that they were being disbelieved and assumed to be 'scroungers'.

> *I always got the impression that I was lying, making it up and was an inconvenience to them.*

> *Why do they not believe my doctor and consultants? …why do they think I am a scrounger?"*

The wider social context is also relevant, and it could be argued that the messages that the general public get about benefit claimants (as mentioned in Chapter 3) has an impact on the attitudes and assumptions brought into each WCA, and that this applies to both those being assessed and those doing the assessment.

As Chapter 3 explained, the WCA had its origins in the Labour government's welfare reform agenda which emphasised disabled people's 'rights and responsibilities' with, initially, a focus on strengthening anti-discrimination legislation and putting in place assistance for disabled people to move into paid employment. The policy agenda soon turned to emphasising 'responsibilities', accompanied by an insistence that many of those claiming incapacity benefits were "a new generation with manageable mental health or musculoskeletal conditions" (Freud, 2007, p.27) and an increasing emphasis on conditions and sanctions. When the Coalition government replaced Labour's New Deal and Pathways to Work programmes with the Work Programme there was an even greater emphasis placed on conditions with the accompanying sanction of withdrawal of benefits (Dwyer et al, 2014).

Politicians - both Labour and Conservative - justified the increasing role of conditions and sanctions by focussing on how long-term disability benefits

encouraged a 'dependency culture' and that many people on these benefits were suffering from a 'poverty of aspiration'. Such justifications were essential for ensuring public acceptance of the withdrawal of benefits when someone didn't meet the attached conditions. One consequence was the inclusion of disabled people in negative attitudes towards benefit claimants in general: as Chapter 3 argued, the claim that 'the unemployed' were not meeting their social obligation to seek work was now frequently applied to disabled people.

We have already seen that media coverage and social attitudes towards disability benefit claimants had become increasingly negative as the welfare reform agenda developed and was implemented. Research also concluded that this type of media representation had a noticeable negative impact on disabled people themselves: "Disabled people are feeling threatened by the changes in the way disability is being reported and by the proposed changes to their benefits and their benefit entitlements. These two are combining and reinforcing each other" (Strathclyde Centre for Disability Research and Glasgow Media Unit, 2012, p.5). When I carried out research on disabled people's experiences of cuts in benefits and services for my MA dissertation, focus group and survey respondents spontaneously mentioned that, in their experience, social attitudes towards disabled people had become more negative (Morris, 2012).

Research commissioned in 2012 on benefits stigma identified three different types:

Personal stigma: a person's own feeling that claiming benefits is shameful

Social stigma: the feeling that other people judge claiming benefits to be shameful and to confer a lower social status.

Institutional stigma: stigma that arises from the process of claiming benefits.

(Baumberg et al, 2013, p. 12).

The authors concluded that while most people claiming benefits do not feel that it is shameful to do so and do not consider themselves to be 'undeserving',

social stigma is common and institutional stigma is widespread (Ibid., Chapter 2). This research also pointed out that the assumption that someone is not 'really disabled' and therefore not 'deserving' is often easy for the general public to make because the majority of claimants have impairments "that are not apparent on a first meeting while nearly half of new claimants have fluctuating conditions" (p.87).   People with non-evident and/or fluctuating conditions who are applying for ESA are aware that having a non-evident impairment or illness made them vulnerable to being disbelieved, illustrating the institutional stigma which is an inherent part of the WCA.

> *I felt like I was lying if I said everything was like my bad days but if I admitted to good days I was scared I'd be judged fit based on these.*

The focus group discussions ranged between anger and despair at both the social stigma they experienced and the institutional stigma which was felt during the process of claiming ESA.

> *It's inhumane and degrading. You have to justify yourself on paper, you try to give medical evidence and they ignore it. I find the whole process degrading.*

> *I used to think people were exaggerating, but they're not. You're made to feel you're not worth it.*

> *The assessment made things worse for me. I felt I was told it's my fault, if you can't work it's because of your attitude, if you had a better attitude then you'd be able to work.*

Many survey respondents similarly recorded how the WCA process had a negative impact on their self-esteem: as one person wrote "*The form makes me feel worthless*". A profound sense of injustice was also commonly expressed.

> *They don't want to make the process fair, stress free, they want to make it hard, impossible and as stressful as hell.*

> *They don't seem to care about disabled people, just care about pushing them off benefits and into work when they're not capable of working.*

I wouldn't wish the whole process on anyone, the whole process needs looking at and changing. It's not a system that's fair.

This sense of injustice illustrates that people did not feel personal stigma was attached to claiming ESA in that they generally believed that their experiences of impairment and/or illness entitled them to the benefit. However, the process of applying could be a disabling experience. As the last chapter established, respondents often found the experience distressing: "*It was one of the most traumatising experiences I've been through in many years.*" This is partly related to the common feeling, as discussed above, that *"it seemed he was just trying to 'catch me out' rather than care what was wrong with me"* and partly to what was seen as the inappropriateness of the questions asked:

The questions are just so irrelevant to anything other than a non disabled or sick person's idea of what disability and sickness is. It's like the ducking stool test if you float you're a scrounger, if you drown you're sick…

It was also the case that a number of respondents found the process of having to emphasise how 'unable' they are, which they felt they had to do in order to get a benefit to which they felt they were entitled, was a source of considerable distress.

It forces you to concentrate on how bad - how dire your health/situation is - and trying not to concentrate on that is what keeps you alive.

The process of elaborating on every difficult and often humiliating detail of my life, exacerbated my depression.

I survive my daily life by thinking about what I can do on my good days, yet this critical, long and intense document [the ESA50 form] focused on my worst day, a very depressing experience.

7.5 Inadequate redress

It was traumatic, humiliating, and exceptionally stressful. I had a doctor's note and a statement from my last employer stating I was not fit for work, but my claim was denied and I had to appeal and go to a tribunal, which

left me with no income for nearly 2 years, because I wasn't able to claim JSA in the meantime.

Appeal took over 6 months. No income other than what my parents gave me. I was homeless and had to rely on a good friend for a roof over my head. I was suicidal throughout all this.

The outcome of the WCA has a significant impact on a person's life. It determines whether and how much of an income replacement benefit they get and whether they are subject to conditions and sanctions which can potentially lead to a total loss of income for a period of time. The sanctions system - which is applied to those found 'fit for work' and those placed in the Work Related Activity Group of ESA - has been called "a secret penal system" where "decisions on guilt are made in secret by officials who have no independent responsibility to act lawfully" and where those who are sanctioned have no access to representation or meaningful redress (Webster, 2015).

Although people applying for ESA do have some access to redress if they feel the decision on their claim is wrong, this access has been steadily diminished in recent years. At the point at which ESA and the WCA were introduced, if someone was unhappy with the decision on their claim they could appeal to an independent tribunal, called a 'First Tier Tribunal', run by the HM Courts and Tribunals Service and in the early years of the WCA, there was a high number of appeals lodged by ESA claimants. Although Tribunals increased the number of days they sat, there were still 145,200 cases outstanding in 2011/12 (MyLegal, 2012), attempts were made to recruit another 145 Tribunal judges (Judicial Appointments Commission, 2012) and it was reported that a total of £66million was being spent on hearing appeals (Wright, 2013).

It took 14 months waiting for appeals at the end of which it was overturned.

In 2013, in an attempt to reduce the numbers of people appealing to a Tribunal, the DWP introduced a new stage to the process of appealing a decision: Mandatory Reconsideration, where a claimant must formally ask DWP to reconsider their decision before proceeding to appeal. This was followed by a

dramatic reduction in the number of appeals of WCA outcomes (Social Security Advisory Committee, 2016, pp.23-24). The government's Social Security Advisory Committee concluded that, if Mandatory Reconsideration had not been introduced, the rate of appeal would have been higher and expressed concern that both their own evidence and that of DWP indicated that claimants found the process complex, daunting and lengthy.

Drawing on evidence from a wide range of organisations, the Committee detailed a number of problems with the process of Mandatory Reconsideration, some built into the process - such as the very short timescale for making a formal request - while others suggested poor practice by DWP staff - such as people "being told by helpline staff that there was no point in putting in an MR request because, without additional medical evidence, the decision would definitely not be overturned" (Ibid., p. 29). The Committee identified many ways in which improvements needed to be made to the MR process, including the need for external oversight.

The number of challenges being upheld at the Mandatory Reconsideration stage was initially quite high but subsequently declined, though it is not clear that this is because the WCA process had improved. When Mandatory Reconsideration was first introduced in 2013, the overturn rate of Fit to Work decisions was 45 per cent but by 2016 it had declined to 11 per cent. The DWP told the Social Security Advisory Committee that "the fall over time is attributed to a 'combination of low registrations' in the beginning and 'time needed for new operational practices to settle down'" (ibid., p.32). There is still a high overturn rate of ESA group decisions (46 per cent) - usually where people have been put in the ESA Work Related Activity Group and have appealed to be put in the Support Group - although these are smaller in number.

The validity of the decisions at the MR stage is called into question by the fact that, although the success rate of over-turning a decision at MR has fallen, the success rate for over-turning a decision when people proceed to a Tribunal remains high. Statistics on appeals indicate that, at the time of writing in 2017, where people appeal to a Tribunal following Mandatory Reconsideration of a Fit

to Work decision, 62 per cent of decisions are overturned (DWP, 2017, p.1). This, and the many problems with the MR process identified by the Social Security Advisory Committee, would tend to indicate that MR does not guarantee effective access to redress if someone wishes to challenge a decision.

Some people found the entire process so traumatising that they felt unable to appeal or were even advised against it to do the impact on their mental health:

> *It's awful. So bad that it made me worse than I was before. My gp and psychiatrist advised me to drop my appeals rather than risk my health deteriorating any further.*

Effective access to redress also depends on having access to expert advice and assistance but the availability of such services has declined in recent years. There has long been recognition that when people have assistance to appeal benefit decisions, for example from a Citizens' Advice Bureau or a Law Centre, they are more likely to win their appeal. Where claimants have representation at Tribunal hearings the success rate for overturning the original decision is on average 63 per cent and can be as high as 74 per cent, according to data released by the Ministry of Justice as a result of a Freedom of Information request (Ministry of Justice, 2013). However, it has been increasingly difficult in recent years for claimants to get access to advice on claiming benefits and representation at Tribunals.

In 2016, the government's Social Security Advisory Committee concluded that "Following the passing of the Legal Aid, Sentencing and Punishing of Offenders Act 2012 (LASPO) – legal aid for the purposes of social security advice has all but disappeared in England and Wales" (Social Security Advisory Committee, 2016, p.10). This was confirmed by the Ministry of Justice who admitted in a Memorandum published in 2017 that:

….prior to LASPO, advice for legal issues associated with the payment of welfare benefits was in scope of legal aid. LASPO removed this from scope, with a few small exceptions. As a result, the numbers in receipt of legal aid for advice and assistance on welfare benefits issues has fallen

from 83,000 in 2012–13 to 440 in 2016–17 (Ministry of Justice, 2017, p.45).

The Social Security Advisory Committee also noted that "Since 2009, nearly 100 Citizens Advice offices have been lost in England and Wales through closure or merger, driven at least partially by cuts to local authority budgets and legal aid" and that "the Chief Economist of Citizens Advice estimated they had seen 120,000 fewer people as a result of reductions in legal aid" (Ibid. p.10). At the same time, the government's 2016 Budget included additional funding to enable the DWP to be represented at Tribunals hearing appeals of ESA and PIP decisions (HM Government, 2016, p.103).

Now I've got to go to appeal I don't think I can cope with it all even though my mum is trying to help but they keep making it so difficult for her saying she needs to be an appointee but I don't lack capacity.

Had to take the original claim to tribunal, which overturned the decision in 10-15 minutes. Without the support of a charity, I'd almost certainly of ended up homeless.

There is considerable evidence, which is also reflected in the experiences of respondents to this research, that a decision-making process which has profound implications for someone's life chances is characterised by an inadequate right and access to redress.

7.6 Removal of relevant clinical expertise

It appeared clear that the word of my GP and other healthcare professionals had no worth compared to the 20 minutes of box-ticking by the ATOS "doctor".

It is not just disabled people's expertise which is removed from the process of establishing eligibility for ESA (as discussed above) but also to a large extent, relevant medical expertise. As previously mentioned, in the 1990s, individuals' own GPs were removed from the process of determining eligibility for long-term out-of-work sickness benefit on the grounds that they were too 'subjective'. Initially, doctors were employed by the government's medical service and given

the task of assessing eligibility but once the assessment process was outsourced to a private company, the job was opened up to nurses and physiotherapists. Only 15 per cent of assessors employed by Maximus, the current contractor, are doctors (House of Commons Committee of Public Accounts, 2016, p. 5).

As Chapter 5 described, the theoretical framework which informs the WCA assumes that knowledge of the individual and their medical history, or expertise in their particular condition, is not required as the aim is to carry out 'objective' assessments of functional limitations, aided by a computer programme.

> *Beyond me what was understood by the assessor, it felt like talking to someone who'd never met a deaf person before.*

The House of Commons Public Accounts Committee heard evidence in 2016 of how assessors had often "an incomplete understanding of particular conditions, such as fluctuating and mental health conditions" (House of Commons Committee of Public Accounts, 2016, p. 5). Unsurprisingly, therefore, one of the problems identified by respondents was that many of the people carrying out the WCA do not have the knowledge or expertise in the impairments and/or illness that the person they are assessing experiences. One person whose WCA was carried out by a physiotherapist had an entirely different experience when the Tribunal hearing the appeal included someone with relevant expertise:

> *The appeal tribunal featured an actual psychiatrist and took ten minutes to realise I was entitled to ESA.*

The unequal power relationship within the WCA assessment process is often, therefore, characterised by the lack of expertise and knowledge of the person who yet has the role of determining the nature of the disabled person's experience and the extent of their functional limitations. A number of critics of the WCA have argued that a person's GP and/or medically qualified specialist in their particular condition should have a key role in determining whether someone is fit enough to work (e.g. Disabled People Against the Cuts, 2012). However, the Royal College of Psychiatrists has found that "It is now

uncommon for the DWP to write to clinicians asking for written evidence"
(Royal College of Psychiatrists, 2014, p.1) and the onus is on claimants to
supply such evidence.

Eighty per cent of people responding to the online survey felt that the questions
they were asked in the face to face interview did not enable them to explain
how their condition affected their ability to work. The DWP state that the most
common reason for decisions being over-turned at appeal is because
information was presented to the Tribunal which was not available at the
assessment (Stone, 2016). Given the rigid, computer-driven nature of the
assessment, and the fact that in many instances the assessor will not have
relevant clinical expertise, it is perhaps not surprising that claimants are often
not enabled to provide the information required to make a sound decision on
their fitness for work.

> *They basically just go through the form again and ask all the same
> questions. They show no real interest in finding out about your condition
> and how it affects you. They ask a question, get an answer, move onto
> the next question. There is no discussion, just checkboxes.*

> *I felt I was asked questions that were not at all relevant to my situation.*

There were some circumstances where respondents indicated that HCPs did
not totally rely on the LiMA programme to arrive at their assessments of fitness
to work. In these cases, however, unless the HCP happened to have clinical
knowledge of the claimant's condition they needed to rely on the
supplementary information provided when submitting the ESA50 form. It helps
if the claimant is aware of the way the assessment is carried out and can
provide information in a way which mitigates the shortcomings inherent in the
process.

> *It's a rare and poorly understood neurological condition. Second
> assessment I was aware that Lima only allowed muscular-skeletal which
> is totally wrong. Had to rely on assessor reading & understanding the
> background info I submitted.*

Farcical box ticking exercise where unqualified people are enabled by DWP to overrule doctors and my psychiatrist. They assessed me as having no issues because I am articulate so I scored zero points which was changed to 20 when the decision was reversed at appeal.

From my perspective the HCP need to be less focused on the LiMA screens and talk to the person sitting before them. There needs to be a genuine conversation about the person and how their conditions impacts their lives. Simply asking a list of preprepared questions will never be adequate.

The difficulties caused by the removal of relevant clinical expertise from the assessment process is compounded by the fact that the DWP Decision Maker, to whom the assessor's report is passed and who makes the decision on eligibility, does not have relevant expertise either. This may partly account for why DWP Decision Makers challenge very few of the reports which are subsequently judged to be of an unacceptable standard (House of Commons Committee of Public Accounts, 2016, p.5) - despite the DWP's evidence that "mistakes mainly related to report decisions not corresponding to the evidence" (Ibid., p.11).

Supporting evidence, from health professionals who have relevant expertise and knowledge of the claimant, can be very important but neither the DWP nor Maximus emphasise this to claimants. DWP 'encouragement' to send such evidence is swiftly followed by a warning that there is a time limit for returning the ESA50 form (to which the evidence would need to be attached), despite the fact that it can take time to get written evidence from GPs and consultants (and can be expensive as many charge for their reports): "Claimants are encouraged to send any evidence they have with the questionnaire to Medical Services. Failure to return the questionnaire on time may result in loss of benefit" (Department for Work and Pensions, 2016). The only reference on Maximus' website to supporting evidence is in the answer to one of their 'Frequently Asked Questions':

My GP doesn't know very much about me. Can another Healthcare Professional provide evidence of how my condition affects me?

Yes, you may provide evidence from another Healthcare Professional. This might be a consultant or specialist doctor, psychiatrist, specialist nurse such as a Community Psychiatric Nurse, physiotherapist, occupational therapist, social worker, support worker, personal assistant or carer (Health Assessment Advisory Service, n.d.).

Even when supporting evidence is provided, the emphasis on the WCA itself providing the most 'objective' evidence means that information from professionals who know the person concerned is not always given adequate consideration.

Went to my appeal with the same documentation ATOS refused. They awarded my ESA with 21 points immediately. That's a big difference. Had they have taken notice straight away of the medical evidence I provided I wouldn't be in the state I am in now.

7.7 Government policy aims prioritised over both clinical judgement and disabled person's expertise

There was no help or understanding about limitations, the staff didn't come across to me as having any experience and it was a "tick box" exercise to stop as many disability claimants as possible.

As Chapter 3 explained, the replacement of Incapacity Benefit with Employment and Support Allowance, and the Personal Capacity Assessment with the Work Capability Assessment, was part of the Labour government's commitment to reduce the numbers on long-term out-of-work benefits by 1 million. Such an ambition flowed from the aim of delivering increasing numbers in employment because, at that point, the unemployment rate stood at a little over 5 per cent, which is more or less 'full employment', but the 'economic inactivity' rate stood at 21 per cent (Freud, 2007, p. 49). This meant to keep the balance of a reserve army and prevent any pressure on wage inflation therefore required a reduction in the numbers who were 'economically inactive', and by then the largest group of these were those in receipt of Incapacity Benefit.

This government priority, which was also adopted by the Coalition government of 2010-2015 and then by the Conservative government, and the way that it has influenced the roll out of ESA, is a particularly important context for the experiences of the WCA recounted by respondents to this research. It is especially important for explaining the sense of injustice that many felt in that they often could not understand why their particular barriers to employment had not been recognised.

From the early days of the introduction of the Work Capability Assessment there were individual stories brought to the public's attention of people being deemed ineligible for ESA, yet who were patently not capable of working. As we have seen, there were high levels of successful appeals in the early years and there was considerable controversy about the way Atos carried out assessments. The DWP and Atos both denied that there were targets applied to how many claimants would be declared 'fit for work', although DWP's initial contract with Atos stipulated that only 11 per cent of applicants were expected to be placed in the Support Group (Franklin 2013). What was eventually exposed - as a result of both identified and anonymous whistle-blowers and Freedom of Information requests - was a 'norm-based' system which, in practice, meant that assessors were very aware of the targets that they were expected to meet (Ibid).

A Conservative MP, when the Labour government's legislation was going through the House of Commons in 2007, identified the dangers of the ESA assessment process becoming a norm-based system:

> I can imagine circumstances...in which a future Minister, under financial or even political pressure, might wish to say, 'We will introduce a norm. We are not going to have, by definition, more than 1.5 million people on employment and support allowance,' and the tests will, in effect, be geared to deliver that result.

> (Quoted by Franklin, 2013, p. 1)

In fact, it would appear that this is precisely what happened, as Franklin later exposed. Atos adopted a management information tool, which assumed

national trends in terms of how many people were expected to be placed in the Support Group, and used this to audit not only the performance of the different regional offices (taking no account of different levels of ill health and disability in different parts of the country) but also the performance of individual assessors. Franklin explains how the system worked:

> Deviation from a narrow range of 'averages', (deviation from the 'norm'), is not tolerated and leads to a 'target audit' process on that individual practitioner. This leads to practitioners closely monitoring the per centage of cases they have placed into various 'outcomes'. Once they have placed, say, 15 per cent of claimants into the support group in a week they are very much less likely to put the next seriously ill or severely disabled claimant they see that week into the deserved support group, as to do so would take the practitioner's weekly figures away from the 'norm' and would be very likely to draw the wrath of their manager upon them through the medium of oppressive and intimidating 100% audit (Franklin, 2013, p. 7).

As whistle-blowers revealed, assessors were put under a lot of pressure to conform to these 'norms', being required to re-write their reports and subject to 100 per cent audits if they put 'too many' people in the Support Group. One doctor was asked a number of times to change his reports so that claimants would be awarded a lower number of points. He finally resigned and went public with his concerns following one particular incident, as he told *The Guardian*:

> "It was clearly wrong, medically," he says. "I had more mental health experience than most of the staff at Atos; I was supposed to be a lead on it. The two people who were telling me to change my report weren't. I had seen the person; they hadn't. She had chronic psychotic illness, going back about 20 years, in and out of hospital, on very strong medicines. Talking to her, she couldn't concentrate, she rambled, she had some odd ideas about things. A classic example of an only partially treated, chronic psychotic person. She fully deserved points. I was specifically told to amend the report. It wasn't: 'You ought to think about changing it'. I was

sent two emails both telling me: 'You need to amend the report'," he says (Gentleman, 2013).

The prioritising of government policy aims over clinical judgement also contributes to the removal of clinical expertise from the assessment which was identified in the above discussion and it means that professionals are inhibited from acting as the allies of disabled people that they could potentially be. In their earlier writings, Finkelstein and Oliver had both identified the potential for professionals to develop a role of being allies of disabled people, of working in partnership with them. Over time, however, both realised that this had not happened and that instead many professionals in a range of contexts were becoming deskilled and subject to rigid bureaucratic rules, spending more time filling in forms than listening to their clients and using their professional skills. Finkelstein, for example, wrote of how social services budget restrictions transformed professionals "into rule-following technicians who rigidly follow a covert cost-cutting agenda" (Finkelstein, 1999, p.2), and forced one from whom he sought a service to behave "like an automated technician with no freedom to decide what was appropriate for me on the basis of her own professional assessment" (Finkelstein, 1999, p.5).

The context in which WCA assessors carry out their work - the norm-based system created by the requirements of a government policy - similarly makes it hard for them to use what professional expertise they have or to act as allies of disabled people in the way Oliver and Finkelstein describe and, instead, constrains them into a role of 'rule-following technicians".

The assessor was more focused on getting yes/no answers than understanding complex health problems.

The priority given to the government's aim of reducing the numbers in receipt of ESA means that the expertise of both professionals and disabled people is downgraded. It is unlikely to be a coincidence that the two benefits which have the highest success rate in overturning original decisions - when they are challenged at independent tribunals - are ESA and Personal Independence Payments, both of which have been the subject of explicit government policy

aims of reducing the numbers who are awarded these benefits (Social Security Advisory Committee, 2016, p.13).

Conclusion

Since the All Work Test, there has been a disconnect between the assessment criteria for out-of-work disability benefits and the likelihood of actually getting employment. This research has examined how, in the context of the Work Capability Assessment, this disconnect would seem to be compounded by the removal of both disabled people's expertise and that of relevant clinical professionals from the process, and also by the prioritising of Labour, Coalition and Conservative governments' aim of reducing the numbers of claimants in order to push more people into the reserve army of labour, and to reduce public spending.

In addition, the research has demonstrated how a denial of agency is a crucial part of how the WCA is carried out and the decisions made by assessors as to whether someone is 'fit for work'. This denial of agency is played out by the unequal relationship between the 'disability analyst' and the disabled person. At the heart of that relationship is the privileging of the so-called 'objective' assessment by the disability analyst and the computer programme which means that not only is account not taken of the disabled person's expertise in how their impairment and/or illness affects them, but their account of their experience is treated as 'subjective' and 'contentious'.

As the current validating device, the WCA determines who is considered eligible to enter the needs-based distribution system and who must be compelled to be in the work-based system. Its ideological framework outlined in Chapter 5, in combination with the pressures resulting from the material reality of the current stage of capitalism, have resulted in a process which this research would suggest actively works to discriminate against disabled people. It is a process which not only does not capture someone's capacity to work (and refuses to acknowledge the role of work itself in affecting this capacity) but also actively causes harm and distress and is in itself a disabling experience. This is inevitable when considering both the ideological framework of the assessment – one which views the individual's experience of their own body as

'contentious' – and the motivation for the assessment in the first place and the role it plays within the political economy. It is an assessment designed to ensure the continued function of capitalism, helping to discipline labour in two ways. It controls the active reserve army of labour, thus acting as a control on wage inflation. In addition, it is key to maintaining the principle of less eligibility, in that it serves as a warning to people to sell their labour or else be subject to a distressing and disabling assessment which may leave them materially worse off and facing the increasing conditionality of out of work benefits.

Successive governments have wanted to reduce the numbers receiving out of work disability benefits for economic reasons, both to increase the active reserve army and to reduce public spending. They have repeatedly framed this as being about 'making work pay', yet there are no real efforts to tackle the barriers which exclude many disabled people from the labour market, which includes the very nature of capitalism. Instead the desire to reduce the claimant numbers is not to improve the lives of those claimants, but to adhere to the needs of capital. Those who move off benefits into work commonly move into low paid, insecure jobs with little access to either sick pay or pensions, and which lack options of progression (Kemp and Davidson, 2008, p 225). These lead to what Kemp and Davidson refer to as the "low pay, no pay" cycle which in turn contributes to poor health. Yet there has been a distinct lack of policies aimed at addressing the type and nature of work that disabled people are likely to do and very little acknowledgement of the role that working conditions play in creating and exacerbating poor health. Moreover, the sole policy which might help address the employment barriers facing disabled people - the 'reasonable adjustments required by anti-discrimination legislation - is significantly restricted by the criteria that any adjustments must not place too great an economic burden on the employer (a point also made by Russell, 2001, writing about the American with Disabilities Act).

Chapter 8: Conclusion

This thesis has drawn together and built upon previous research and analysis in three different areas of study which, it has argued, are all essential to understanding how the determination of who is eligible for out-of-work benefits in the United Kingdom has been driven by developments in the political economy and why there is a consequent disconnect between current policy approaches to disability and disabled people's lived experiences. While there are limitations to the survey data gathered for the purposes of this research (as discussed in Chapter 4) the key findings reflect both the independent reviews of the WCA and other research looking at claimant's experiences. Moreover, as highlighted in the Introduction, the thesis is distinctive in that it goes beyond illustrating how ESA claimants experience the WCA, being centrally concerned with why the WCA takes the form that it does. In so doing it has argued that neither previous developments nor the current situation can be understood without a wider analysis which places disabled people's experiences in the context of past and current developments of the capitalist mode of production. This concluding chapter summarises the findings of the research and analysis before examining the question of 'what next' for the validating device and considering whether there is a better way forward.

8.1 Summary of findings

This research set out to examine what the relationship is between changes in the UK labour market and out-of-work disability benefits and why this relationship is important. Its hypothesis was that changes in the assessments for out-of-work disability benefits are related to the political economy and that they have resulted in a disconnect between disabled people's lived experience of both their impairments and the labour market, and the official approaches to these benefits. It has argued that until this disconnect is reconciled the government's aim to reduce the disability employment gap and recently announced intention of getting 1 million more disabled people into work by 2027 will not only be impossible, but their current approach will only increase the distress and misery that clearly comes through in the survey, focus group and interview responses.

The research has used a historical materialist analysis to show how the key to this disconnect is disabled people's relationship to the current mode of production. It has also used Stone's concept of validating device to explore how the state uses assessments of capacity to work in order to allocate people into the needs based or the work based distribution systems. It has examined why the validating device takes the form that it does and how the political ideology associated with this validating device has changed over time, arguing that has been largely dependant on the needs of capital.

Analysis of both changes in the labour market and in policies on out-of-work disability benefits since the 1970s showed how consecutive governments have been motivated to develop and implement policies to pull disabled people into the active reserve army of labour as a way of increasing the supply of labour and bringing down, and keeping down, the level of inflation and of public expenditure. Chapters 2 and 3 described how disabled people moved from largely being considered part of the stagnant or dead weight of the surplus population to active members of the reserve army: from 'helpless victim' to potential 'scrounger'. However, both chapters also argued that the rise in out-of-work disability claimants and the subsequent failure of the numbers to fall is directly linked to changes and developments in the labour market.

As the inability of governments since the 1990s to reduce the numbers on out-of-work disability benefits has demonstrated, there has so far been a limit to which disabled people can be pulled into the active reserve army of labour. An analysis of the current direction of travel of the labour market - the increase in low paid, insecure, low control, high effort jobs - argued that disabled people are less likely to be recruited to such jobs, and even if they are they are less likely to be able to sustain such employment. Changes in the occupational structure of the labour market also mean that there are diminishing employment opportunities and there are an increasing number of jobs the characteristics of which often have a disadvantageous impact on people's physical and mental health. This is the material reality facing disabled people, a reality which, as Chapters 5, 6 and 7 illustrated, is largely ignored in the context of the

development and implementation of the current validating device, the Work Capability Assessment.

Chapter 5 scrutinised six documents to understand how the political ideology informing the WCA developed. It analysed how an approach to long term health conditions adopted by some medical practitioners was utilised in the development of validating incapacity to work. This approach - the biopsychosocial model - purported to encompass both psychological and social, as well as biomedical factors, in the treatment of long term health conditions. However, as this approach was developed in the context of changes to the validating device, it became part of a politically constructed reality which defined the restrictions associated with 'common health problems' as a matter of 'choice and intent'. The WCA thus distinguishes between 'real disabled people' - those with 'severe and permanent impairments' - and people with 'common health problems' who aren't 'really disabled' and whose behaviour can supposedly be influenced by incentivising them to seek work. This 'reality' is constructed to be compatible with the demands of a neoliberal approach to the economy - the need for a flexible labour market, to increase the active reserve army of labour, and to keep public expenditure under control in the context a declining tax base and increasing demand on the public finances. The politically constructed reality represented by the WCA is at odds with disabled people's actual experiences because, this thesis has argued, these experiences are determined not by political ideology but by the reality of impairment and/or long-term health conditions limiting the extent to which their labour can be exploited in the current stage of capitalism.

The purpose of the WCA as a validating device is to determine who should be expected to engage in waged labour in order to meet their income needs (and thus pulled into the active reserve army of labour) and who should be given state support to meet their income needs because their impairment or ill health prevents participation in waged labour (and treated in effect as part of the 'stagnant surplus population'). However, the analysis of survey data on what disabled people's experience is of the WCA, presented in both Chapters 6 and 7, clearly demonstrates that from the point of view of those being assessed the

WCA does not actually assess the likelihood of someone being able to engage in waged employment. This is because the assessment is of functional limitations which bear little or no relationship to the practicality of either doing an actual job or getting and retaining a job. In addition, as is clear from respondents' experiences, a number of problems with the quality of both the form and the face to face assessment make it difficult for applicants' lived experiences to be fully and appropriately recognised.

One of the main reasons for this disconnect between what the validating device is measuring and the actual lived experience of disabled people is that, despite the insistence of consecutive governments that they understand, accept and aim to use the social model of disability in their policy formations, they focus solely on an individual's functional limitations and are entrenched in the medical or individual model of disability. There is a mistaken belief "that people are disabled by their impairment, rather than the structures of capitalism that privilege the non-disabled over the disabled body" (Grover and Piggot, 2016, p11). This is shown by the main conclusions of the data generated for this research which showed that the WCA does not gather information related to the practicalities of paid employment; and that the format of neither the ESA50 form nor the face to face assessment enable people to provide the information they felt assessors needed to know to fully understand their problems with engaging in waged labour. Another very important message that came from the research was that the very process of applying for ESA was both creating and exacerbating poor health, particularly mental health. This would appear to confirm other research on the mental health of ESA claimants (Barr et al, 2016; Marks et al 2017).

Chapter 7 examined how the theoretical and conceptual framework of the Work Capability Assessment impacts on disabled people's lived experience. The survey and focus groups' responses generally indicate that when the State and its agencies are in total control of the construction and administration of a 'validating device' then the experience is inherently disempowering. Labour, Coalition and Conservative governments have all argued that their welfare reform agenda is about encouraging so-called independence. Dependency is

defined as being reliant on state benefits but, as Chapter 7 highlighted, the actual process of assessing eligibility for support, and of services intended to enable employment, is experienced as a taking away of agency, of making people dependent on the state's role in determining 'fitness to work'. The neoliberal assumption that people are 'rational actors' who will act out of self-interest has generally been used to justify cutting back on benefits in order to ensure that they have the financial incentive to take up employment and become 'independent'. As Chapter 3 explained, this was, for example, the explicit reason given for cutting the amount of benefit payable to people in the ESA Work Related Activity Group. Yet, as the analysis of the experiences of the WCA presented in Chapter 7 illustrates, it is the process by which the State judges who is eligible for out-of-work benefits which takes away agency from those subjected to it.

It is also clear from the data analysed in Chapter 6 and 7 that, rather than helping people become less dependent on benefits or improve their health and move into work, the WCA makes people feel as if unless they are very ill and incapacitated they are not deserving of support. It has made them afraid of doing things which may increase their likelihood of working in the future in case this is taken as evidence that they can work now. The support offered by the government does not attempt to engage in what makes working difficult, instead it focuses on people's attitude towards work. It individualises the problem. It is largely based on an idealist view of the world where someone's beliefs are what determines their likelihood of moving into work, not the material reality of what may be making work difficult, whether that is impairment or illness related or related to the material reality of the demand for labour or of working conditions.

8.2 What next for the validating device?

The numbers of people of working age with chronic illness/long-term health conditions is projected to increase significantly in the coming years (Bajorek et al, 2016), something acknowledged in the 2017 White Paper (Department of Work and Pensions/Department of Health, 2017). There will undoubtedly be continuing attempts by governments to reduce the levels of economic inactivity

associated with such conditions. There is limited evidence that previous or current policies have had much success so far and it would appear that recent developments do nothing to reverse the profound disconnect between the 'logic' of governments' labour market and social security policies, and the reality of a significant number of disabled people's experiences.

When Labour came into office in 1997, there was general political agreement with Tony Blair's mantra - "Work for those who can; security for those who cannot" (Department for Social Security, 1998, p.iii). Over the course of the next 20 years, repeated attempts at reforming the validating device have been aimed at reducing the numbers who warrant 'security for those who cannot' work. The category of 'those who can' work (i.e the reserve army of labour) has been significantly extended by the creation of the Work Related Activity Group, and subsequent changes which reduced the level of benefit for those placed in the WRAG to that of Job Seekers Allowance and increasingly applied conditions to receipt of ESA/Universal Credit. Recent developments seem to be aimed at continuing this process.

8.2.1 The 'health and work conversation'

As we have seen, there have been five reviews of the WCA, adjustments to the training and instructions to assessors, and a change in contractor. In 2017, the opposition Labour Party said it was committed to abolishing the WCA while the Conservative government's current policy seems to be to retain it but add a 'Health and Work' assessment of what support a person would need to 'get back to work'. However, this 'support' is not about the material reality facing disabled people. It does not seek to identify any equipment, aids or adaptations to the workplace or work patterns that someone might need. It does not seem to even attempt to assess whether someone needs better access to healthcare.

Rather, as discussed in Chapter 3, the Health and Work Conversation is geared towards the motivations and attitudes of individuals and is merely the latest attempt to 'recraft' disabled people as willing workers. A Freedom of Information request resulted in the release of more information about the

Health and Work Conversation in 2017, prior to its introduction for all new ESA claimants. This revealed that the intention of the conversation, which will take place before the WCA, is to "build motivation and resilience and increase the likelihood of work-related activity and ultimately finding work" (Benefits and Work, 2017). A key part of the 'conversation' is for the Work Coach to identify the claimant's 'values' and the main exercise that people are asked to do is one which seeks to address "loss of confidence and motivation". A Health and Work Conversation booklet sets out a four steps exercise that claimants will be required to work through with their Work Coach, where they are asked to identify a 'want' (something they want to do), 'outcome' (how they will feel on achieving it), 'obstacles' and 'plan'. The booklet (and the suggested script for the Work Coach) tells the person what kind of 'obstacle' they are expected to identify: "It's something within you that you have some control over, and you're able to do something about it, even though it is difficult. It could be a habit, something you believe in, or a feeling you have" (Department for Work and Pensions, 2017e, p.4).

Although there is a suggestion that external obstacles, such as housing problems or debt, may be identified in other parts of the 'conversation', this main exercise and the suggested script for the Work Coach makes clear that identifying an external obstacle to a desired outcome is not acceptable (Department for Work and Pensions, 2017f). Instead the message to claimants is that the "obstacle" to be focussed on is "something within you" (Department for Work and Pensions, 2017e, p.4). The following instructions to Work Coaches illustrate how they should do this:

> Note 1: Sometimes claimants choose "Wants" that only have external obstacles they don't have any control over. For example, they might say they want to go to language classes, but there are no classes near them. In this situation, check whether there is another internal obstacle stopping the "Want". For example, you could suggest to the claimant that they do a language class online. If they lack the computer skills to do an online course, that is an internal obstacle they can address by doing a computer training course.

If the "Want" really has no internal obstacle, ask the claimant to choose a new "Want" which does have an internal obstacle.

Note 2: Sometimes claimants have obstacles that are always present. For example, a claimant might say their goal is to visit a friend more often, and identify their chronic pain as an obstacle to this goal. Because the pain is always present, work with the claimant to identify about specific ways to overcome this issue. For example, you could say "Your "Want" is to visit a friend. When is the next time you could visit and how will your pain make it difficult?" The claimant could say they will visit their friend on Saturday, and then make a plan to deal with their pain well enough to be able to visit their friend by that day (Department for Work and Pensions, 2017f, p.15).

Such instructions are an illustration of an attempt to reconstruct the way disabled people experience both their impairments and the disabling barriers they face. Moreover, this reconstruction takes place in a context where people's self-defined experience is treated as contentious and as a matter of 'choice and intent' (as discussed in Chapter 5).

There has been much criticism of the way Work Capability Assessments are carried out. However, it is the contention of this research that the problem is not with the technicalities of the assessment, nor with the quality of the assessors – although these could undoubtably be improved. Instead, the underlying problem is with the theoretical and conceptual framework, and with the over-riding political priority of reducing the numbers on long-term benefits in order to both increase the size of the active reserve army of labour and reduce public expenditure. The consequence is a mechanism - the validating device - which attempts to take away from the individual their ability to self-define their experience of their body, their mind and of how they experience the world around them.

The treatment of people's own experience of their restrictions as contentious and the privileging of the assessors and the DWP Decision-maker's judgement accords with the way conditionality is being applied to the receipt of benefits in

general. As Edmiston argues, this could be called neoliberal paternalism, in that welfare reforms have sought to "recraft unemployed individuals into 'active welfare subjects'" by "cultivating capabilities and orientations contributing towards market assimilation" (Edmiston, 2017, p. 317). The Work Capability Assessment, and now the Health and Work Conversation, is about the 'recrafting' of disabled people who are not in waged work, whereby the agencies of the State determine what a person's 'functional limitations' are, whether they are to be treated as 'deserving' or 'undeserving' and whether they need to be 'incentivised' to seek employment. The recrafting of ESA claimants into members of the active reserve army of labour requires the State to redefine the barriers they face into 'something within' the individual (their lack of 'motivation' and 'resilience') which prevents them from being willing and able workers. The consequence is that a person's self-defined experiences are treated as invalid.

In this context, there is no room for considering whether workplaces are 'fit' for disabled people, no room for recognising that the type of occupations where disabled people are most likely to find work are diminishing in number. There is also no room for recognising that the working conditions associated with the jobs that are increasing in number are not only difficult for people with long-term health conditions and/or impairments to do but are also, in themselves, associated with some of the 'common health problems' that the WCA treats as 'contentious'. There is a failure to recognise the material reality facing people with impairments and/or ill health in the UK today and it is this which creates a profound disconnect between how 'disability' is officially recognised and disabled people's lived experiences.

8.2.2 'Improving Lives: the future of work, health and disability'

At the end of 2017, the Conservative government announced yet another policy initiative aimed at pulling more disabled people into the active reserve army of labour. Previous Labour, Coalition and Conservative governments had announced their intention of 'getting 1 million disabled people off benefit' (see Chapter 3). Now the current Conservative government claims they will get 1

million more disabled people in work by 2027 (Department of Work and Pensions/Department of Health, 2017, p.8). This reframing of the commitment could be taken as a tacit recognition that the aim of reducing those on out-of-work disability benefits has proved impossible to deliver since it was first articulated in the 1990s. However, the general direction of travel has not changed in that the focus of this most recent policy represents just another stage in the way disabled people's reality is being political constructed.

In the last decade or so, there has been increasing emphasis on how work is good for a person's health. The November 2017 publication *Improving Lives* very much defines work as a 'health outcome' with this contention running throughout the report and including a heading specifically aimed at "Raising the profile of work as a health outcome with healthcare professionals" (Department for Work and Pensions/Department of Health 2017, p.37). The report was co-authored by the Secretary of State for Health and the Secretary of State for Work and Pensions, which reflects previous recommendations to integrate the welfare system and health support (e.g. Black, 2008). It also calls for more joined up thinking between the welfare system, the workplace and healthcare. However, this is largely an extension of the ideas around the Health and Work Conversation discussed above and the idea of employment being a health outcome is absolutely central to the entire report.

Choosing to aim for 1 million more disabled people in work by 2027, rather than a reduction of the disability employment gap, suggests that the government may have recognised that there are limits to which disabled people's employment opportunities can be improved. It is entirely possible that 1 million more disabled people will be in paid work while at the same time the disability employment gap remains the same - or even increase - as the numbers of people with long term health conditions are predicted to increase and that the types of jobs available may themselves increase the likelihood of developing certain health conditions/illnesses (see discussion in Chapter 2).

Interestingly the *Improving Lives* White Paper itself does acknowledge that "The prevalence of disability among people of working-age has risen in recent

years and is likely to rise further with an ageing workforce" (p 5) which is a change from the frequently voiced disbelief of the Conservative government in the early 1990s and the Labour government of 1997-2010 that so many people could be disabled when the general health of the population was supposedly ever improving. The report also notes "that the wrong kind of work can be damaging" (p 7) and they accept that a lot of the feedback from their consultation called for a change in the WCA. The government now says they have committed to "improving assessments" (p 17), although it is still uncertain as to whether they intend to replace the WCA. Another welcome statement is a reference to those with fluctuating and multiple conditions/impairments and their right to support.

It is also welcome that there is a commitment that Access to Work will be "significantly enhanced", that mental health support and sign language provision will be particularly strengthened and equipment will be portable between jobs. In addition, there is mention of Personal Budgets and potential peer-led support. However, what these will involve is not made clear and, despite the acknowledgement of the importance of Access to Work, there is a cap on the amount of funding available to each claimant regardless of whether this means it will fail to meet their adjustment needs. Crucially the key focus on work as a health outcome does not seem to address how and why work might be difficult. Such difficulties might stem from someone's experience of how their body or mind functions, but they may also be related to the disabling nature of work in itself - the insecure, low control/high effort features which have increased within the labour market, as discussed in Chapter 2. Moreover, there are few acknowledgements of wider issues impacting on individual's ability to work, such as housing, education, social care and debt. Although the report does reference other future reports on education and social care in particular which may address these, overall it seems the policy priority of getting someone into work is to be pursued in isolation from any meaningful consideration of the very real barriers that many people face.

Not only is work as a health outcome central to the policies set out in this document, but there are references to people needing to build or improve

resilience and to "overcome fixed beliefs about their abilities" (e.g. Department for Work and Pensions/Department of Health, 2017, p.17). There is nothing in the report which suggests any changes to the WCA which would address the fundamental problems stemming from the ideas underpinning the assessment, which were examined in Chapter 5. Nor are there any changes which would address the experiences of the survey, focus groups and interview participants as set out in Chapters 6 and 7, experiences which made clear that the WCA failed to understand either their impairments or what made work difficult and, in many cases, contributed to making their health, particularly mental health, worse.

There have already been concerns raised over one of the main ideas which is meant to help those with mental health conditions move into work. This is the policy of putting employment advisors (Work Coaches) into Increasing Access to Psychological Therapies (IAPT) centres (such as GP surgeries or other community health centres), which are now the main source of psychological support available on the NHS. As evidenced by Chapters 6 and 7, many people who have experience of applying for ESA have become distrusting and often scared of government assessments and officials, and by placing people who will be considered part of this process in places where people go to get support it could make them fearful of seeking support (Inclusion London, 2017, p.23). Disability activists protested when the London Borough of Islington set up a joint project with the local Clinical Commissioning Group and Job Centre Plus to place employment advisors in GP surgeries in 2015. They expressed concern that employment was being set as a clinical outcome, employment coaches would have access to and could input information onto a patient's medical record, and they feared that while involvement was to be voluntary it would eventually be part of the conditionality imposed on benefit claimants (Disabled People against the Cuts, 2016). The project has now been extended to a larger randomised control trial seeking to recruit 1000 people with long-term health conditions, despite the earlier phase only placing 6 people in employment out of the 59 who took up the offer of employment support (London Borough of Islington, 2017).

8.3 Is there a better way forward?

As this research has shown, the current policy and assessment process for determining who is eligible for out-of-work disability benefits is not working for either the government or for those applying for and claiming it. It is not working for the government as they are finding it increasingly hard to reduce the numbers claiming by any substantial amount and are reacting to this by narrowing the eligibility criteria, so making it harder to claim, reducing the monetary value of the payments and by ever more intensive measures to push people into employment. Which in turn is making it not work for those applying and claiming it by disregarding their own experiences of their impairments and ability to work and making their lives harder and more miserable. The next part of this chapter will look at what changes could potentially improve this situation.

8.3.1 Co-producing a 'real-world' assessment?

At the June 2017 general election, the Labour Party committed to scraping the WCA and have since made various statements about working with disabled people to produce a replacement. However, at the time of writing (late 2017) they have yet to produce anything concrete showing how they would do this. If such an assessment was to stand any chance of mitigating the problems of the current one it would need to be genuinely co-produced by disabled people who had direct experience of the WCA. Co-production is a concept which has been part of the social care agenda for a number of years but has very rarely been raised as a possibility in the context of social security policies. In the social care context it has been defined as:

> an equal relationship between people who use services and the people responsible for services. They work together, from design to delivery, sharing strategic decision-making about policies as well as decisions about the best way to deliver services (Think Local Act Personal, n.d.)

Co-production is therefore a significantly different relationship from the more traditional consultation process, where government makes proposals which have already been worked up. The process would also need to recognise that

disability (i.e. the experience of disabling barriers) is not homogenous and would have to ensure that a wide range of impairments and experiences were included amongst those involved in co-producing a more appropriate form of assessment.

Such an assessment would need to be based on disabled people's lived experiences and not treat these as contentious and therefore invalid, as the WCA does. This could help to return autonomy and control to disabled people to both self-define their experience of their impairment/health condition and the adjustments they require. As Chapters 5, 6 and 7 showed, the current assessment process considers disabled people's experiences of their impairment/health condition as not just contentious, but irrelevant. It is very hard for an assessment to either not feel oppressive and hostile, or to truly engage with someone's lived experience, when the assessment itself is grounded in a framework which views that experience as deceptive.

As Chapter 7 discussed, if health professionals can work in a true partnership with someone, where a disabled person's "experiential knowledge" of their own body is used "as the foundation for learning, with the professional's expert knowledge at the service of the client" (Williams, 1993, p.12), then there is potential for the assessment to be both a more positive experience and more likely to truly understand someone's impairment/health condition and their barriers to work. It was noticeable that the few positive experiences spoke of feeling understood and listened to.

If an assessment was truly co-produced it is also more likely to ensure that the questions asked are relevant to both someone's impairment/health condition and how this impacts on them finding and sustaining waged labour. In so doing it should also include what have been described as 'real world' tests where age, work experience and skills, as well as local labour markets are taken into consideration (Baumberg et al, 2015). This would be particularly important given the correlation between rates of claims and regional variations in labour markets. It will be important to consider not just the general availability of jobs locally but the types of jobs that are available and whether an individual had the

necessary skills and experience. Arguably a better assessment and support system would not attempt to create 'incentives' to push people into employment but would work with them to decide what, if any, type of work may be possible without causing additional harm to their health and what support would be required to make this possible. It would involve also working with employers and perhaps having available continuing advice, support and advocacy throughout the duration someone is in employment.

It is noticeable that a number of the issues raised by research participants as to why the WCA fails to capture or understand their impairments/long-term health conditions and their impact on someone's ability to engage in waged labour echo the concerns of disabled people's organisations had when IVB was first introduced. As mentioned in Chapter 3, some of these concerns were that it "fails to take account of the reality of there ever being the kind of employment opportunities for which a person with those disabilities is suited" (Strickland, 1994, p.24); that "Non-medical factors are relevant and should be taken into account. Other factors which interact with disability have an impact on work capacity." (p. 25); and that "isolating the ability to perform work-related tasks cannot take into account the realities of actual workplaces and the demands of employers for a flexible and reliable workforce" (p. 28). Perhaps if disabled people had been listened to from the start of the introduction of these functional assessments, we may not have ended up with an assessment process which, as this thesis has shown, causes distress and harm to many of those going through it.

However, whilst such an assessment operates within the current economic system it will struggle to move away from locating the problem needing to be addressed as lying with disabled people. The necessity of the administrative category of disability and the role it plays in labour discipline, by both controlling the reserve army of labour and embedding the principle of less eligibility to compel people to sell their labour, will ultimately take priority over disabled people's experiences.

8.3.2 'Social worth' should not be defined by economic productivity

Even if a new assessment of incapacity to work was genuinely co-produced, it would still operate within a system where individuals' worth to society is based on their participation in waged labour. Over the past twenty years governments have increasingly moved towards work as an obligation of citizenship (Grover and Piggot, 2015) with the assumption that relying on benefits means failing to fulfil such obligations. This was clearly signaled when Labour took office in 1997, when Prime Minister Tony Blair announced the intention to "rebuild the welfare state around work" (quoted by Hills, 1998, p.28) and the message increasingly became that: "a citizen cannot truly be an equal member of the community if he or she is reduced to a state of permanent dependency on the support of others" (Blunkett, 2003).

Associated with this political ideology is an underlying assumption that waged work is the only 'meaningful activity' for human beings and that any support must be aimed at enabling people to be economically productive. For example, the 2017 White Paper referred to above has a solitary reference to 'meaningful activity' as a goal which might not involve waged work, when it refers to "A country that works for everyone needs to help ensure that all who can work or undertake meaningful activity have the chance to do so" (Department for Work and Pensions/Department of Health, 2017, p.3). Yet the sentence immediately after this infers that the only purpose of providing support to disabled people is to enable them to work: "And that the right care and support is in place to enable all to thrive in work throughout their working lives" (Ibid).

Some disability activists have argued that disabled people are more likely to be treated as full citizens if there was a focus on activities, other than waged work, which, as 'meaningful activities', produce the same social benefits that work purports to. A central part of this would need to be a moving away from considering that waged labour, which is driven by the desire for maximising as much surplus value and profit as possible, is the only way people are considered to be valuable to society. As Barnes has argued "when work is organised around a different set of principles such as social necessity and interdependence people with impairments are included in, rather than excluded

from, the workplace" (Barnes, 2012, p 7). Barnes makes the case, for example, for reconfiguring as 'work' the numerous everyday tasks many disabled people have to do (Barnes, 2012). Using Corbin and Strauss (1988) he discusses how different tasks which disabled people have to do to manage and incorporate their impairment into their day to day lives could be viewed as work. The idea of disabled people's role in employing personal assistants (PAs) and in designing and delivering user led services is one which is also picked by Roulstone (2015) who argues that it is a redefinition of economic productivity which is required to address disabled people's social and economic exclusion. He points to the "gradual historic redefinition of domestic labour as non-productive" (p 267) as an example of how productivity is redefined to benefit the dominant economic system and says that economic productivity:

> if interpreted broadly as adding value to communities, stimulating economic activity, aiding environmental improvements and improving a social skill set, then the array of direct payment employment (of personal assistants [PA]), involvement in access groups, civic contributions and unpaid voluntary work all contribute in a way that, although difficult to monetise, is clearly adding value to the community, economy and wider workforce skill set. (Roulstone, 2015, p 268).

While such suggestions would potentially make a difference to disabled people's inclusion in society and help fight against the rhetoric of posing 'scroungers' against 'strivers', this still fails to address those disabled people who may not be able to make such contributions. Also, although it may challenge what is considered economic productivity, it still accepts the premise of neoliberalism which is that everyone is judged and valued by their economic productivity. Barnes' argument that if work was based on social need rather than economic profit would help shift the emphasis away from economic productivity, and a re-configuration of what work means would also be beneficial. However, this still works on the premise of work, however defined, being central to meaning and value in life regardless of whether it has social or economic value. As Grover and Piggott (2015) argue:

there is a need for a way forward that does not simply replace economic production with social production as the means by which the contribution of individuals is judged. An approach is needed that will allow for the observation that perhaps there are people who will, no matter how production is defined, never be as productive as others (p 247).

8.3.3 Questioning the need for a validating device

We have already seen how the current validating device - the WCA - invalidates disabled people's self-defined experiences. However, a more fundamental question needs to be asked about the very concept of an assessment, or a 'validating' device. As this research has shown the purpose of this device is to determine whether someone 'deserves' to be in the needs based distribution system. This effectively means that such assessments are used to validate disabled people's rights to a basic standard of living (through the receipt of an income replacement benefit). There is a fundamental problem with the whole notion of such a device determining whether people are 'deserving' or 'undeserving' - people's social worth and their entitlement to a basic standard of living should not be on the basis of 'validating' how 'dependent' and 'vulnerable' they are.

The validating device itself, therefore, assumes a basic inequality. Although people who are provided with Employment and Support Allowance have their needs 'validated' - their need for an income replacement benefit - the very process confirms them as being unequal within our current economic and political system. They are, according to Marx, the 'dead weight; or 'stagnant surplus', that is surplus to the requirements of capitalism. This of course throws into question any disabled person's social worth - but inevitably follows from the assumption that the only way to contribute to society is to be economically productive, as discussed above. It could therefore be argued that by validating someone's entitlements they are at the same time being invalidated as a full citizen. The validating device produces and reproduces disability - in other words, it creates an experience of social oppression for the people with impairments and long-term health conditions who undergo the process. As

long as this remains a central feature of any assessment of the need for an income replacement payment, it is inevitable that the political ideology associated with social security policies will either implicitly or explicitly denigrate the social worth of those needing to rely on such payments.

8.4 Conclusion

As Marta Russell wrote: "the employment predicament of disabled persons is produced by the economic and social forces of capitalism" (Russell, 2001, p.83). The last few decades have seen some quite dramatic changes in the UK labour market, resulting in diminishing employment opportunities for disabled people. At the same time, associated economic factors (the need for an active reserve army of labour and to bring down the level of inflation and of public expenditure) have motivated governments to develop social security and employment policies aimed at pulling disabled people into the workplace.

The development of, the ideas behind and the implementation of the Work Capability Assessment needs to be understood in this context. In this sense, "social security policy should be understood as a mechanism for buttressing such features of capitalism" (Grover and Piggott, 2010, p.274). In her explanation of needs based and work based distribution systems, Stone (1984) argued that in order to make the work based system function it is crucial that it is seen as the only system which confers social worth, meaning that being placed in the needs based system brings with it an inferior social status. It is this which explains the reason for the enduring strength of the principle of less eligibility, which has remained since the poor laws, and of the increasing tendency to see waged work as the only route to full citizenship. Within such a system those who cannot and do not engage in waged labour will always remain marginalised and face discrimination, both cultural and economic. This marginalisation will particularly intensify when there are pressures to cut public spending on economic support for those who cannot work and the principles of less eligibility are increasingly tightened in an effort to push people from the needs to the work- based distribution system.

There remains a contradiction for disabled people under capitalism where arguably "exclusion from exploitation in the wage-labour system, as the 'deserving poor', lies at the core of disabled peoples' oppression in every aspect of modern life" (Russell & Malhotra, 2002, p 216), yet at the same time by asking disabled people to compete in the labour market, they are being asked to compete within the very structure which disables them. The very role of the administrative category of disability within capitalism is also part of capitalism's many contradictions. Capitalism requires an active reserve army in order to function, and it needs to be able to expand and contract this depending on the requirements of the labour market in order to control wages and as a consequence profits. Stone's analysis of a needs-based and work-based distribution system allows a clear understanding of how entry and exit to the active reserve army can be controlled. This is currently controlled in the UK via the WCA and, as this thesis has shown, this is in itself an oppressive experience which removes autonomy and creates additional distress. As discussed above there are undoubtably some changes to this process which would alleviate some of this oppression and distress. However, these would merely be tinkering around the edges. It is the contention of this thesis that capitalism's requirement that people must be compelled to sell their labour, and the need for a reserve army of labour, means that any validating device will always be an oppressive process whose very purpose is to remove control and to be at the mercy of the state and the requirements of capitalism.

Policies driven by disabled people, both in terms of an assessment of the need for an income replacement, and what work place adjustments would be required, could go some way to mitigate some of the disabling experiences of the assessment and to address some of the disabling barriers to employment. However, unless there are fundamental changes to both the way work is defined and, more importantly, to how individuals' worth, their value, and even their basic humanity is recognised, such changes will only be a sticking plaster on the much larger problems created by the economic and social forces of capitalism.

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Appendix One: Online Survey

Experiences of applying for ESA

Page 1: Survey information and consent

I am a PhD student at the University of Leeds who has personal experience of applying for Employment and Support Allowance and attending a Work Capability Assessment.

My research is looking at changes over time in the way the government defines 'disability' for the purposes of employment-related disability benefits, its relation to the economy, and how this definition compares with disabled people's lived experiences.

As part of this research I am gathering people's experiences of applying for Employment and Support Allowance and in particular the Work Capability Assessment and how well they feel this reflects and understands their lives.

If you have ever applied for Employment and Support Allowance (including if you are not currently recieving it) I would be very grateful if you could complete this short survey. All answers are confidential and anonymous. No information will be shared with any other individual or organsiation and when writing up my research I will ensure that no respondents can be identified. None of the questions are compulsory and you can save the survey to complete at a later time at any point.

I would really appreciate it if you could help with this research. Having been through the process of applying for ESA myself, I know it can be distressing to recall the experience so if at any point you are finding it very difficult to continue please don't.

If you have any further questions please contact me at: ss10rm@leeds.ac.uk

Thank you very much for your time.

1. I have read and understood the above text and agree to participate in the following survey *Required*

- Yes
- No

Page 2: Experiences of applying for Employment and Support Allowance

2. Have you ever applied for Employment and Support Allowance (ESA) and been required to fill in an ESA50 form? (An ESA50 form is the form you are asked to complete when you apply for ESA)

3. How easy did this form make it to explain how your health condition/impairment/disability affects your ability to work?

- ○ Very easy
- ○ Fairly easy
- ○ Fairly difficult
- ○ Very difficult
- ○ Not sure

3.a. Please elaborate if you wish to:

4. Have you ever attended a Work Capability Assessment?

○ Yes

○ No

5. *If yes, when was this? (If you've attended more than one please check all that apply)*

- ☐ 2008
- ☐ 2009
- ☐ 2010
- ☐ 2011
- ☐ 2012
- ☐ 2013
- ☐ 2014
- ☐ 2015
- ☐ 2016

6. *For the last WCA you attended did the WCA assessor say they had any expertise in your particular health condition/impairment/disability?*

- ○ Yes, they said had expertise
- ○ They said they did not have expertise
- ○ They didn't say/I didn't ask if they had expertise

7. *If the assessor said they had expertise, was that evident to you in the assessment?*

- ○ Yes
- ○ To some extent
- ○ No

8. How well did the questions you were asked enable you to explain how your health condition/impairment/disability impacts on your ability to work?

- ○ Very well
- ○ Fairly well
- ○ Not very well
- ○ Not well at all
- ○ Not sure

8.a. Please add any additional comments here:

9. How well did the questions you were asked enable you to explain how your health condition/impairment/disability impacts on your day to day life?

- ○ Very well
- ○ Fairly well
- ○ Not very well
- ○ Not well at all
- ○ Not sure

9.a. Please add any additional comments here:

Page 3

10. Did you submit any additional evidence?

○ Yes
○ No

11. Did you have any problems either obtaining or submitting additional evidence?

○ Yes
○ No
○ Other

11.a. Please elaborate here if you wish to:

○ Yes, and I received it
○ Yes I requested it, but did not receive it
○ No
○ I was not aware I could request it

12. Did you request a copy of the Assessor's report?

○ Yes, and I received it
○ Yes I requested it, but did not receive it
○ No
○ I was not aware I could request it

13. If you did receive a copy of the Assessor's Report how well did it reflect the information you gave during the WCA or on your ESA50 form?

○ Very well

○ Fairly well

○ Fairly poorly

○ Very poorly

○ Not sure

13.a. Please elaborate here if you wish to:

14. Is there anything else you would like to say about your experience of applying for ESA?

15. Is there anything else that the assessor could have asked about to get a clear idea of what your barriers are, or ability is to work?

Page 4: Barriers to work

16. Are you currently in paid employment? (part-time or full-time)

○ Yes
○ No

17. Are you currently doing voluntary work? (Of any kind)

○ Yes
○ No

18. If you are currently doing any form of paid or voluntary work, what factors have helped to make it possible for you to do this? (Please select all that apply):

☐ Flexible working hours
☐ Part time working
☐ Working at home
☐ Adaptations to workplace
☐ Equipment in workplace
☐ Personal (physical) support in workplace
☐ Personal support with confidence/anxiety/mental health issues
☐ Extra time to complete tasks
☐ Employer understands the impact of my health condition/impairment/disability
☐ Fellow workers understand the impact of my health condition/impairment/disability
☐ Ability to attend regular health appointments
☐ Ability to attend irregular health appointments
☐ Accessible transport
☐ Financial help using transport

- □ Personal support to use transport
- □ Support with self-care at home
- □ Support with caring responsibilities
- □ Support/equipment relating to communication
- □ Accessible information

18.a. If there are any factors that are not listed above, please elaborate: *Optional*

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┌─────────────────────────────────────────────────────┐
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│                                                     │
│                                                     │
│                                                     │
└─────────────────────────────────────────────────────┘
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19. If you are currently not in paid employment or doing voluntary work, how important are any of the following to your ability to do either? (please select any which apply)

More info

Please don't select more than 1 answer(s) per row.

	Very important	Quite important	Not important
Availability of paid or voluntary work locally	□	□	□
Availability of paid or voluntary work for which I am qualified/have experience/is suitable for my health condition/impairment/disability	□	□	□
Limitations created by my state of health	□	□	□
Limitations created by my experience of pain	□	□	□
Flexible working hours	□	□	□
Part time working	□	□	□
Working at home	□	□	□

Adaptations to workplace	☐	☐	☐
Equipment in workplace	☐	☐	☐
Personal (physical) support in workplace	☐	☐	☐
Personal support with confidence/anxiety/mental health issues	☐	☐	☐
Extra time to complete tasks	☐	☐	☐
Employer understands the impact of my health condition/impairment/disability	☐	☐	☐
Fellow workers understand the impact of my health condition/impairment/disability	☐	☐	☐
Ability to attend regular health appointments	☐	☐	☐
Ability to attend irregular health appointments	☐	☐	☐
Accessible transport	☐	☐	☐
Financial help using transport	☐	☐	☐
Personal support to use transport	☐	☐	☐
Support with self-care at home	☐	☐	☐
Support with caring responsibilities	☐	☐	☐
Support/equipment relating to communication	☐	☐	☐
Accessible information	☐	☐	☐

19.a. If there are any factors that are not listed above, please elaborate:

Page 5: Demographic questions

20. How old are you?

○ Under 18
○ 18 - 24
○ 25 - 39
○ 40 - 64
○ 65+

21. What is your gender?

○ Male

○ Female

○ Other

○ Prefer not to say

22. What area of the country do you live?

○ London and the South East
○ East of England
○ North East England
○ North West England
○ Midlands
○ Scotland
○ Wales
○ Other

22.a. If you're not sure which area of the country to tick, please tell me what county you live in or your nearest city/large town:

[   ]

23. How would you describe your impairment/health condition/disability? (Please select all that apply)

☐ Physical

☐ Mental health

☐ Learning disability/difficulty

☐ Sensory: vision

☐ Sensory: hearing

☐ Chronic illness

☐ Autistic Spectrum

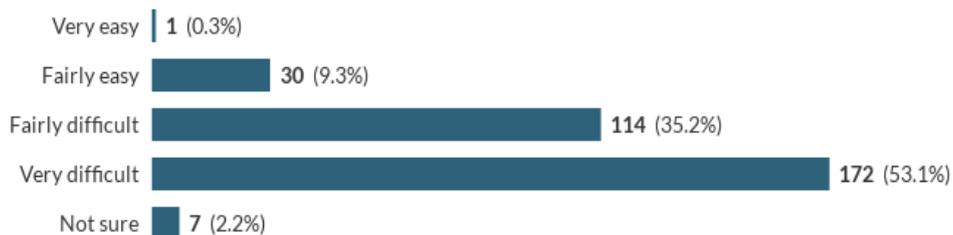☐ Other

Page 6: Finish and submit

Thank you very much for your time and contributions to this research. It is greatly appreciated. If you would like to receive information about the results of this research please email me at: ss10rm@leeds.ac.uk

Appendix Two: Survey Results

Experiences of applying for ESA

(Charts of quantitative answers for questions 2-13 and 16-19)

2. Have you ever applied for Employment and Support Allowance (ESA) and been required to fill in an ESA50 form? (An ESA50 form is the form you are asked to complete when you apply for ESA)

Very easy	1 (0.3%)
Fairly easy	30 (9.3%)
Fairly difficult	114 (35.2%)
Very difficult	172 (53.1%)
Not sure	7 (2.2%)

3. How easy did this form make it to explain how your health condition/impairment/disability affects your ability to work?

Very easy	1 (0.3%)
Fairly easy	30 (9.3%)
Fairly difficult	114 (35.2%)
Very difficult	172 (53.1%)
Not sure	7 (2.2%)

4. Have you ever attended a Work Capability Assessment?
4.

Yes	249 (77.1%)
No	74 (22.9%)

5. If yes, when was this? (If you've attended more than one please check all that apply)

2008	25 (6.4%)
2009	21 (5.4%)
2010	41 (10.5%)
2011	42 (10.8%)
2012	54 (13.9%)
2013	66 (17%)
2014	39 (10%)
2015	60 (15.4%)
2016	41 (10.5%)

6. For the last WCA you attended did the WCA assessor say they had any expertise in your particular health condition/impairment/disability?

Yes, they said had expertise	**27** (10.6%)
They said they did not have expertise	**61** (23.9%)
They didn't say/I didn't ask if they had expertise	**167** (65.5%)

7. If the assessor said they had expertise, was that evident to you in the assessment?

Yes	**3** (2.3%)
To some extent	**13** (10.2%)
No	**112** (87.5%)

8. How well did the questions you were asked enable you to explain how your health condition/impairment/disability impacts on your ability to work?

Very well	**4** (1.5%)
Fairly well	**29** (11.1%)
Not very well	**82** (31.4%)
Not well at all	**134** (51.3%)
Not sure	**12** (4.6%)

9. How well did the questions you were asked enable you to explain how your health condition/impairment/disability impacts on your day to day life?

Very well	**3** (1.1%)
Fairly well	**41** (15.6%)
Not very well	**83** (31.6%)
Not well at all	**126** (47.9%)
Not sure	**10** (3.8%)

10. Did you submit any additional evidence?

Yes	**246** (78.3%)
No	**68** (21.7%)

11. Did you have any problems either obtaining or submitting additional evidence?

Yes	118 (39.3%)
No	148 (49.3%)
Other	34 (11.3%)

12. Did you request a copy of the Assessor's report?

Yes, and I received it	103 (34.8%)
Yes I requested it, but did not receive it	21 (7.1%)
No	43 (14.5%)
I was not aware I could request it	129 (43.6%)

13. If you did receive a copy of the Assessor's Report how well did it reflect the information you gave during the WCA or on your ESA50 form?

Very well	2 (1.2%)
Fairly well	11 (6.8%)
Fairly poorly	26 (16%)
Very poorly	87 (53.7%)
Not sure	36 (22.2%)

16. Are you currently in paid employment? (part-time or full-time)

Yes	39 (12.1%)
No	284 (87.9%)

17. Are you currently doing voluntary work? (Of any kind)

Yes	79 (24.5%)
No	244 (75.5%)

18. If you are currently doing any form of paid or voluntary work, what factors have helped to make it possible for you to do this? (Please select all that apply):

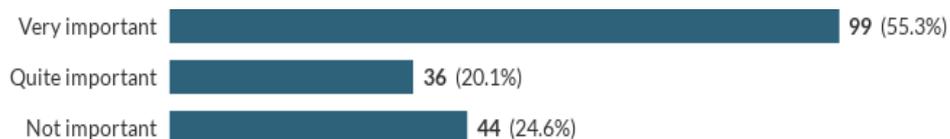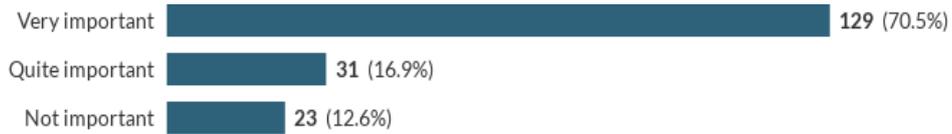| Factor	Value
Flexible working hours	71 (12.2%)
Part time working	58 (10%)
Working at home	43 (7.4%)
Adaptations to workplace	13 (2.2%)
Equipment in workplace	7 (1.2%)
Personal (physical) support in workplace	14 (2.4%)
Personal support with confidence/anxiety/mental health issues	44 (7.6%)
Extra time to complete tasks	28 (4.8%)
Employer understands the impact of my health condition/impairment/disability	65 (11.2%)
Fellow workers understand the impact of my health condition/impairment/disability	53 (9.1%)
Ability to attend regular health appointments	41 (7.1%)
Ability to attend irregular health appointments	43 (7.4%)
Accessible transport	21 (3.6%)
Financial help using transport	22 (3.8%)
Personal support to use transport	11 (1.9%)
Support with self-care at home	18 (3.1%)
Support with caring responsibilities	8 (1.4%)
Support/equipment relating to communication	10 (1.7%)
Accessible information	10 (1.7%)

19. If you are currently not in paid employment or doing voluntary work, how important are any of the following to your ability to do either? (please select any which apply)

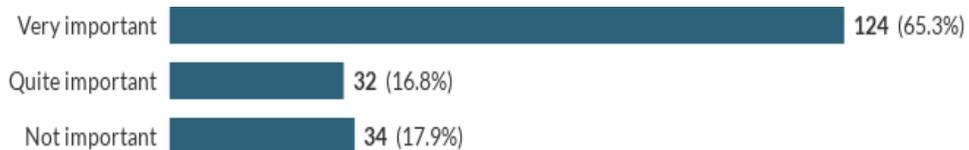*19.1* Availability of paid or voluntary work locally

Very important	99 (55.3%)
Quite important	36 (20.1%)
Not important	44 (24.6%)

19.2 Availability of paid or voluntary work for which I am qualified/have experience/is suitable for my health condition/impairment/disability
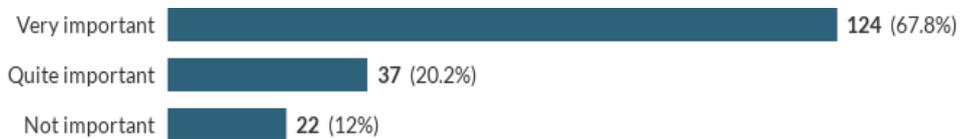
Very important	129 (70.5%)
Quite important	31 (16.9%)
Not important	23 (12.6%)

19.3 Limitations created by my state of health

Very important	180 (90.5%)
Quite important	17 (8.5%)
Not important	2 (1%)

19.4 Limitations created by my experience of pain

Very important	124 (65.3%)
Quite important	32 (16.8%)
Not important	34 (17.9%)

19.5 Flexible working hours

Very important	124 (67.8%)
Quite important	37 (20.2%)
Not important	22 (12%)

19.6 Part time working

Very important	120 (67.8%)
Quite important	30 (16.9%)
Not important	27 (15.3%)

19.7 Working at home

Very important	88 (49.2%)
Quite important	48 (26.8%)
Not important	43 (24%)

19.8 Adaptations to workplace

Very important	68 (40.7%)
Quite important	24 (14.4%)
Not important	75 (44.9%)

19.9 Equipment in workplace

Very important	47 (29.7%)
Quite important	32 (20.3%)
Not important	79 (50%)

19.10 Personal (physical) support in workplace

Very important	56 (34.1%)
Quite important	37 (22.6%)
Not important	71 (43.3%)

19.11 Personal support with confidence/anxiety/mental health issues

Very important	132 (68.4%)
Quite important	31 (16.1%)
Not important	30 (15.5%)

19.12 Extra time to complete tasks

Very important	101 (57.7%)
Quite important	43 (24.6%)
Not important	31 (17.7%)

19.13 Employer understands the impact of my health condition/impairment/disability

Very important	168 (88.4%)
Quite important	14 (7.4%)
Not important	8 (4.2%)

19.14 Fellow workers understand the impact of my health condition/impairment/disability

Very important	149 (78.8%)
Quite important	29 (15.3%)
Not important	11 (5.8%)

19.15 Ability to attend regular health appointments

Very important	117 (65.7%)
Quite important	31 (17.4%)
Not important	30 (16.9%)

19.16 Ability to attend irregular health appointments

Very important	120 (67%)
Quite important	36 (20.1%)
Not important	23 (12.8%)

19.17 Accessible transport

Very important	96 (55.2%)
Quite important	34 (19.5%)
Not important	44 (25.3%)

19.18 Financial help using transport

Very important	99 (55.6%)
Quite important	34 (19.1%)
Not important	45 (25.3%)

19.19 Personal support to use transport

Very important	57 (35.2%)
Quite important	32 (19.8%)
Not important	73 (45.1%)

19.20 Support with self-care at home

Very important	62 (36.7%)
Quite important	38 (22.5%)
Not important	69 (40.8%)

19.21 Support with caring responsibilities

Very important	43 (27%)
Quite important	24 (15.1%)
Not important	92 (57.9%)

19.22 Support/equipment relating to communication

Very important	41 (25.3%)
Quite important	22 (13.6%)
Not important	99 (61.1%)

19.23 Accessible information

Very important	61 (37.2%)
Quite important	37 (22.6%)
Not important	66 (40.2%)

Appendix Three: Survey Demographics

Experiences of applying for ESA
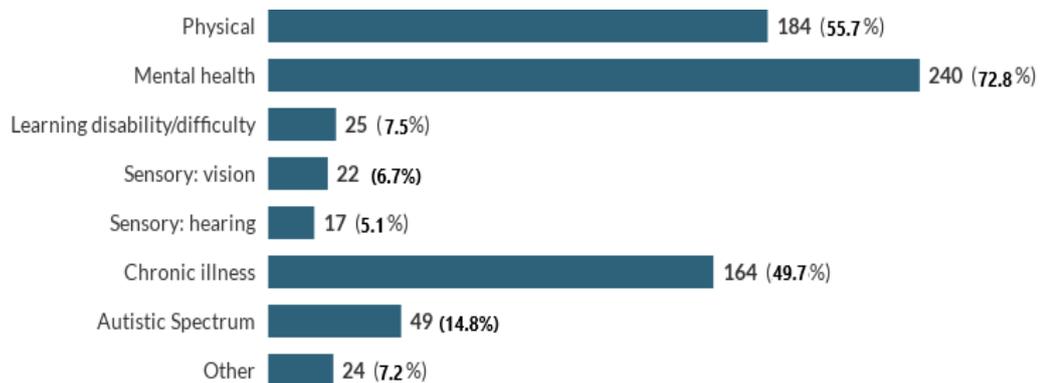
(Charts of quantitative answers for questions 20, 21, 23)

20. How old are you?

Under 18	1 (0.3%)
18 - 24	28 (8.6%)
25 - 39	131 (40.4%)
40 - 64	164 (50.6%)
65+	0

21. What is your gender?

Male	135 (41.8%)
Female	171 (52.9%)
Other	17 (5.3%)
Prefer not to say	0

23. How would you describe your impairment/health condition/disability? (Please select all that apply)

Physical	184 (55.7%)
Mental health	240 (72.8%)
Learning disability/difficulty	25 (7.5%)
Sensory: vision	22 (6.7%)
Sensory: hearing	17 (5.1%)
Chronic illness	164 (49.7%)
Autistic Spectrum	49 (14.8%)
Other	24 (7.2%)

(these add up to more than 330 as people were able to select multiple responses. However, the percentages relate to the total number of respondents who indicated they have that particular impairment/health condition)